

**THE SOCIO-ECONOMIC IMPACT OF HIV/AIDS: A CASE STUDY OF
ELDERLY PEOPLE CARING FOR HIV INFECTED INDIVIDUALS IN
THE UGU NORTH DISTRICT, KWAZULU-NATAL.**

By

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DECLARATION

Submitted in partial fulfilment of the requirements for the degree of Masters in Population Studies in the Graduate Programme in the Faculty of Humanities, Development and Social Sciences, University of KwaZulu-Natal,
Durban, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Population Studies in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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Abstract

This study explores the socio-economic impact of HIV/AIDS on the elderly in the Ugu North District, KwaZulu-Natal. This study employs qualitative methods using in-depth interviews. The sample consisted of 6 females and 6 males aged 60 and above. The respondents were all black. The respondents either had lived or were living with an HIV/AIDS infected individual in their household. The findings of the study indicate that the high prevalence of HIV/AIDS among the younger generation places a huge social and economic burden on the elderly people, especially those who are caring for HIV infected individuals in their households. The findings of the study show that the elderly are carrying a huge burden because of HIV/AIDS. Elderly men and women revealed the trauma of seeing their children dying in front of them. Providing treatment to a sick person, losing a child, loss of income, stigma and discrimination and caring for grandchildren were some of the difficulties faced by elderly people. The results of the study suggest that elderly people should be a key focus of HIV/AIDS discourse.

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List of acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
HIV	Human Immunodeficiency Virus
PRB	Population Reference Bureau
WHO	World Health Organization
TB	Tuberculosis
UKZN	University of KwaZulu- Natal
UNICEF	United Nations Children's Fund
UNAIDS	United Nations Programme on HIV and AIDS
USAID	United States Agency for International Development
STATSA	Statistics South Africa

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Chapter 1

Introduction

1.1 Background

There has been considerable debate with regard to the definition of “elderly” which is differently defined in different societies. The exact definition of an ‘older person’ is nebulous, the majority of scholars use 50 years as the separation point between prime-age adults (15-49), the approximate group most at risk of AIDS, and the beginning of old age (Ainsworth & Dayton, 2003). In defining the elderly, Orimo (2006) uses the chronological age of 65 years old or older, while those from 65 through to 74 years old are referred to as "early elderly" and those over 75 years old are referred to as "late elderly". In South Africa, elderly women receive their pension at the age of 60, and men at the age of 65. WHO (2009:4) declares that “the more traditional African definitions of an older or elderly person correlate with the chronological ages of 50 to 65 years”. For this study, I have decided to consider people who are aged 60 and above to be elderly because very few studies have been conducted to understand how HIV/AIDS affects people who are aged 60 and above. The aim of this study is to examine the socio-economic impact of HIV/AIDS on the elderly.

1.2 The AIDS Epidemic

According to UNAIDS/UNICEF&WHO (2008) approximately 25 million people have died of AIDS worldwide, and another 33 million are currently living with HIV/AIDS. In 2007 alone, more than 2 million people have died from HIV/AIDS worldwide. HIV/AIDS is the leading cause of death in Africa. There were 33 million people living with HIV in 2007, an increase from 29.5 million in 2001 as a result of continuing new infections, people living for longer with HIV, and the general population growth (UNAIDS/ UNICEF &WHO, 2008). The prevalence of HIV/AIDS is high among people who are in their reproductive ages. This has led to a large number of children being left without parents. There are approximately 15 million AIDS orphans today (children who have lost one or both parents to HIV), most of whom live in sub-Saharan Africa (UNAIDS/ UNICEF &WHO, 2008). These children are left in the hands of their grandmothers and grandfathers to care for them. It is suggested that more than 15 million children under 18 have been orphaned as a result of AIDS (UNAIDS, 2009).

The majority of these orphans live in developing countries such as Africa and Asia (UNAIDS 2009). The majority of AIDS orphans who live outside of Africa reside in Asia, where the total number of orphans - orphaned for various reasons – is more than 73 million (UNICEF, 2005).

HIV/AIDS was first diagnosed more than three decades ago. In eight countries in Southern Africa (Botswana, Lesotho, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe) the national adult HIV prevalence is higher than 15% (UNAIDS, 2008). Poverty is considered to be a major contributing factor to poor people especially women engaging in high risk sexual activities. Another factor is gender disparities that exist in Sub-Saharan Africa (Hidden, Whitaker, Floyd & Latimer, 2008). Men still enjoy more opportunities than women when it comes to accessing resources and opportunities. In large urban areas of Southern Africa, various studies over the past eight years have recorded HIV infection rates among female sex workers at levels as high as 68% in Zambia and 50% in South Africa (UNAIDS, 2009). Botswana like South Africa, Lesotho, and Malawi, has a high HIV/AIDS prevalence rate. In 2005 the HIV prevalence rate was 24% in Botswana. In Lesotho the epidemic also remains serious with an estimated national adult HIV prevalence of 23.2 % (UNAIDS, 2009). Angola has the lowest number of people in Sub-Saharan Africa living with HIV/AIDS at 2.5 %. However, in some Sub-Saharan African countries such as Swaziland there has been a slight decline in HIV/AIDS prevalence. A study conducted in Swaziland on pregnant women showed a drastic decline among women attending antenatal care. One study of pregnant women reported a decline from 26 percent in 2002 to 18 percent in 2006 and another study over the same period indicated that prevalence declined from 21 % to 13 % (UNAIDS, 2009). These massive declines in HIV/AIDS are attributed to strong HIV/AIDS awareness campaigns which have brought about behavioural changes. In Swaziland, data from the 2006–2007 Demographic and Health Survey (DHS) suggest a decline in HIV prevalence from 32.4 percent in 2003 to 25.9 in 2006–2007 (UNAIDS, 2009).

HIV/AIDS has left many children without parents in this Sub-Saharan region. High numbers of orphans mean more responsibilities for elderly people because middle age dies early. Since the beginning of the epidemic more than 14 million children have lost one or both parents to AIDS (UNAIDS, 2009). These orphans often face a number of difficulties, and are often exposed to risk factors. Lack of income puts extra pressure on them to contribute financially

to households, in some cases driving them to the streets to work, beg, or seek food (UNAIDS /UNICEF &WHO, 2005).

There are a number of factors which contribute to the rapid growth of HIV/AIDS in the Sub-Saharan Africa region. More 16 % of sexually active men and 3 %t of sexually active women reported more than one partner over the previous 12 months (Torre, Khan, Eckert, Luna, & Koppenhaver, 2009). Multiple partners are common in many societies in Africa, especially among men. This then puts women at high risk of HIV infection. Torre et al. (2009:3) state that “the widespread practice among men of maintaining multiple relationships is contributing to the high levels of HIV infection among women, especially young women”. The low economic status of women in the Sub-Saharan Africa is another stumbling block in the war against HIV/AIDS. Women’s economic status exposes them to high risk activities. Torre, Khan, Eckert, Luna & Koppenhaver (2009) affirm that adolescents and young adults who engage in sexual relations with partners who, by virtue of their age and longer sexual history, are more likely to be HIV positive. In addition, Nakangu et al. (2008) attest that poverty influences people to engage in sexual activity as a survival strategy. Cultural norms also play a huge role in the spread of the AIDS epidemic in this region. For instance young girls are expected to demonstrate their fertility at a very young age. In their study, Nakangu, et al. (2008) observes that women are required to be submissive to men, hence they cannot question their faithfulness or refuse them sex.

Sub-Saharan Africa is the hardest hit region, and is home to two-thirds (67%) of people living with HIV/AIDS (UNAIDS/ UNICEF &WHO, 2008). South Africa and Botswana have the most people living with HIV/AIDS (UNAIDS/UNICEF &WHO, 2008). The impact on women is more significant in Sub-Saharan Africa, where women represent 59% of all adults living with HIV/AIDS, and this number is growing in certain regions (UNAIDS/ UNICEF &WHO, 2008). Gender inequality makes women more vulnerable than men.

In South Africa, the estimated overall HIV prevalence rate is approximately 10.6%. There are approximately 5.2 million people living with HIV in South Africa. For adults aged 15–49 years, almost 17% of the population is HIV positive (Statistics South Africa 2009). There has been a relatively limited focus on the impact of the epidemic on the elderly population. The high rate of HIV infection in young people places a huge burden on the elderly. WHO (2000) reports that almost 60% of orphans in South Africa are being cared for by their grandparents.

This is also supported by United Nations Development Programmes (2008:7) which note that “the growing HIV/AIDS pandemic has resulted in the loss of the middle generation, leaving the elderly more vulnerable to a lack of care”. Usually, children are the ones who are expected to look after their parents when they grow old, by giving them care and support. Due to the high HIV/AIDS prevalence among the middle age groups, the elderly are now carrying the burden of caring for their sick children and grandchildren. The impact of the worldwide AIDS epidemic on persons age 50 and over has received little consideration except in the United States (Knodel et al, 2003). The high HIV/AIDS prevalence on the young generation has taken elderly people out of the HIV/AIDS discourse. There has been limited focus of the impact of the epidemic on the elderly population. However, the high rate of HIV infections among young people places huge burdens on elderly people.

The impact of HIV/AIDS on AIDS orphans

Studies suggested that orphans are more likely than non-orphans to reside in large, female-headed households where more people are dependent on limited income earners (Monasch & Boerma, 2004). Since HIV/AIDS is killing young adults, in other words, people who are likely to be parents, this leaves many children with no parental guidance at a tender age. For a child to lose a parent or both parents is an emotionally draining and traumatic experience. The death of a parent to AIDS can have negative consequences for a child’s access to basic necessities such as shelter, food, clothing, health and schooling (Monarch & Burma, 2004). AIDS orphans often face a number of challenges, including having to delay their schooling, exploitation through hard labour, sexual abuse, and discrimination from other children. Young girls might be forced to drop out from school in order to support their siblings. Children orphaned by AIDS may miss out on school enrolment, have their schooling interrupted, or perform poorly in school as a result of their situation (Matshalaga, 2002).

The majority of AIDs orphans might be HIV positive themselves; infected through mother to children transmission, which usually happens when the baby is still in the mother’s womb or during child birth. Orphans may put pressure on older relatives who become their primary carers, they may have to relocate from familiar neighborhoods, and siblings may be split apart, all of which can harm their development (UNAIDS, 2009).

The impact of HIV/AIDS on the elderly

WHO (2000) reports that most of orphans in South Africa are being cared for by their grandparents and the experience of raising a second generation weighs heavily on the elderly. Usually children are the ones who are expected to look after their parents when they grow old, by giving them care and support. But, due to the high HIV/AIDS prevalence among the young adult, the elderly are now carrying the burden of caring for their sick children and grandchildren. However, in Sub-Saharan Africa where HIV/AIDS prevalence is high there has not been much information about how HIV/AIDS affects the elderly. Numerous studies suggested that elderly people are caring for the sick, the dying and the children orphaned or made vulnerable by the HIV/AIDS pandemic (Nhongo, 2004). This indicates that the elderly are not only carrying the burden of caring for the sick but some also have to provide care to grandchildren who might be sick as well. Whilst elderly people have become the primary carers for millions of orphaned children, it should also be recognized that in many cases there is some degree of reciprocity in the care and support relationship and that in some situations children have become the primary carers of their older relatives (Nhongo, 2004).

1.3 Rationale for the Study

South Africa has a high HIV/AIDS prevalence rate. According to ASSA (2003), AIDS is the leading cause of death among 15 to 49 years old. While the age group most likely to be affected by HIV in any population is those between 15-49 years old, who tend to constitute the most economically active section of the population, the old and the very young also feel the impact on their lives (Seeley & Pringle, 2008). The high prevalence of HIV/AIDS among this age group places much pressure on the elderly because they have to look after sick individuals. This has led to the elderly becoming crucial role players in holding the family together. Since the HIV/AIDS prevalence is high among this generation, it calls for an investigation into the impact on the elderly who are caring for sick individuals. This study seeks to understand coping mechanisms used by elderly in responding to socio-economic difficulties. This study will provide government and AIDS policy makers with insight into how the HIV/AIDS-affected population, particularly the elderly because most studies indicate that they are the undermined key role players in the struggle against HIV/AIDS, are not recognized in terms HIV/AIDS interventions. Government has implemented a number of HIV/AIDS awareness programs and campaigns directed at the infected group, but they have neglected affected elderly.

Why the focus on the elderly?

Many older people face the consequences of AIDS-related illness and deaths among their own children and other relatives, and of the wider social and economic changes brought by the epidemic (Hosegood & Timaeus, 2008). Studies have revealed that older persons are increasingly being affected by HIV/AIDS directly and indirectly, through knowledge of and interaction with family and friends who are living with HIV/AIDS (Fouad, 2004:7). Since the prevalence of HIV/AIDS is higher among people of reproductive ages in South Africa, it has resulted in a number of interventions focusing on young people leaving elderly people out of the discourse. While some older persons are at risk or infected, a much larger number are affected through the illness or death of their adult sons and daughters and other family members (Zuehlke, 2009). This is further supported by Knodel et al. (2006: 8) who states that “despite their considerable caretaking role, the elderly remain largely hidden from the international HIV/AIDS agenda”. Despite the high prevalence of HIV/AIDS in South Africa, there have been very few studies conducted in order to understand how HIV/AIDS affects the elderly. Soon after young adults get infected by the virus, the elderly have to assume the role of caregivers to their adult children until the infected persons die. In places where access to treatment is widespread, the burden of personal caregiving for older persons to HIV-infected adult sons and daughters is substantially reduced while the potential for older aged parents to provide important treatment support to their adult children is greatly enhanced (Zuehlke, 2009). Most studies have shown that when younger parents die they leave their children with the elderly who often have to assume the role of parents to their grandchildren. The increasing burden of morbidity and mortality among the young is likely to increase the importance of the practical contributions made by the elderly to their households (Hosegood & Timaeus, 2006). Because it is assumed that they are not at risk of contracting HIV, the elderly have received minimal programmatic and policy attention (Knodel et al, 2006).

1.4 Objectives of the Study

The main objective of the study is to investigate the socio-economic impact of HIV/AIDS on the elderly in rural KwaZulu-Natal.

The specific objectives are:

- to examine the socio-economic impact of HIV/AIDS on the elderly in rural KwaZulu-Natal;

- to explore the challenges and concerns faced by the elderly with regard to HIV/AIDS in rural KwaZulu-Natal;
- to examine the strategies used by the elderly to protect themselves against the socio-economic impact of AIDS in rural KwaZulu-Natal.

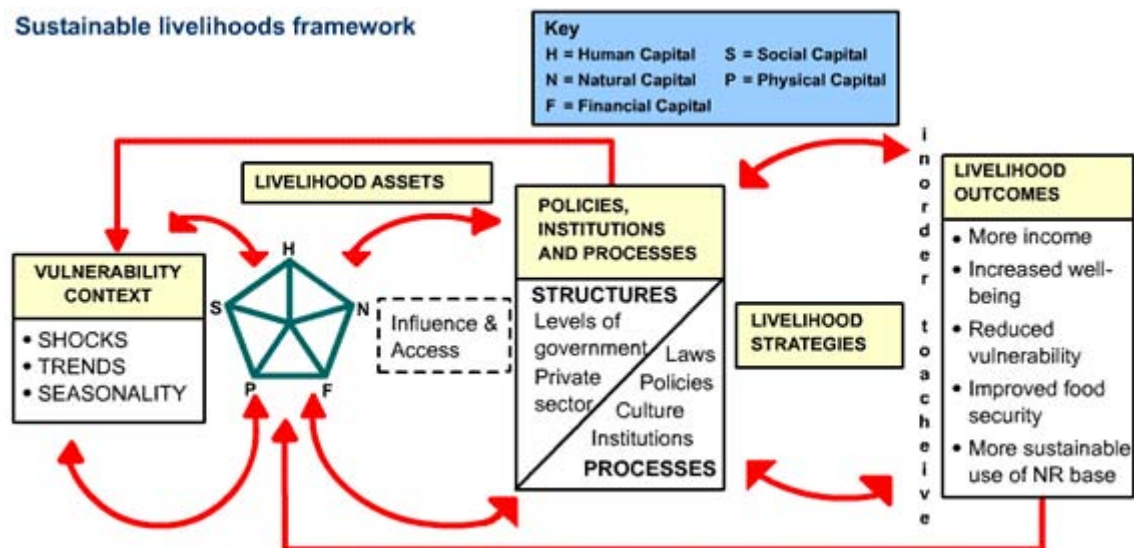
This study employed qualitative methods using in-depth interviews to provide rich information about the impact of HIV/AIDS on elderly men and women.

1.5 Conceptual Framework

For this study I have used the sustainable livelihood framework which is useful for understanding the socio-economic impact of HIV/AIDS on the elderly who care for HIV infected and affected individuals. Chambers & Conway (1992:3) argue that a “sustainable livelihood is a means of living, and the capabilities, assets and activities required for it”. In addition, Chambers & Conway (1992:4) state that “a livelihood is deemed sustainable if it can cope with and recover from stress and shocks and maintain or enhance its capabilities and assets both in the present and in the future, while not undermining the livelihoods of future generations”. The same sentiments are provided by Appleton (2000) who argues that HIV/AIDS is more than a health issue that demands prevention and care for the sick it is also a livelihoods issue. If AIDS-depleted households are not the focus of particular support, the precarious livelihoods of survivors are likely to deteriorate under the impact of the epidemic. This indicates that HIV is not only about sickness, but it can cause social and economic instability as well, which then undermine the livelihood of household. The elderly may face severe social and economic difficulties due to HIV/AIDS. For instance, an illness of a family member due to HIV/AIDS will result in increasing medical expenses. This may mean that the elderly have to sell valuable property in order to pay the medical costs for sick individuals. Seeley & Pringle (2008) state that the socio-economic vulnerability may result in the adoption of survival strategies that increase the risk of HIV transmission. Sometimes elderly may be forced to put up for sale their valuable assets in order to obtain access to treatment and other basic commodities. Seeley & Pringle (2008) found that land may be sold to cover medical fees, funeral costs or everyday household expenses. This suggests that the elderly may be obliged to sell things that they value, like land and stock, in order to be able to purchase necessities for treatment and to meet funeral costs. The majorities of the elderly are

not economically active and can no longer go to the fields and plough, and hence they rely on their pensions to survive.

Figure 1.1



Source: Chambers & Conway (1992)

Generally, HIV/AIDS affects households in two major ways, namely socially and economically. On the social level, households have to deal with issues around stigmatization, social exclusion and disintegration of family structures and social support networks (Ganyaza-Twalo & Seager, 2005). This means that the family has to spend more time caring for the sick person, and the family structure may disintegrate if the deceased person is a breadwinner. Often families, who are known to contain an HIV positive person, are socially excluded from the community. If the deceased person was the sole breadwinner, it can lead to a crisis in the household. On the economic level, households and the surviving members have to pay for medical costs and funeral expenses and, if the deceased was a breadwinner, there will be further financial impacts in the form of a loss of income (Ganyaza-Twalo & Seager, 2005). These are major challenges faced by the elderly who have to endure the pain of burying their children. This can affect the livelihood of the elderly. A study carried out in northern Thailand shows that HIV/AIDS has severely impacted the livelihood of the elderly who were caring for HIV/AIDS individuals in their households. Elderly parents often suffer

the loss of financial resources that their sick or deceased adult children previously provided (Knodel, 2004). The loss of income to the households has been reported a major concern for many elderly who are caring for sick individuals. The majority of the elderly with sick or deceased individuals, who were household income earners, are very worried about the future.

The sustainable livelihoods approach offers a holistic way of addressing the HIV/AIDS epidemic which promotes discussion across sectors and disciplines, to look not just at the impact on health but also the impact on social support, finances, housing, land-use and land tenure (Seeley & Pringle, 2008). There is recognition that HIV/AIDS may have an impact on other family members, especially if the sick individual is the only person who has been working in the household. Family members may struggle to pay the bond for the house and other basic commodities. This approach tries to address such issues. Most studies have shown that HIV/AIDS has long term consequences in a dysfunctional family system. Seeley & Pringle (2008:5) argue that “policies, projects and programmes which seek to arrest the spread of HIV/AIDS and mitigate the impact of the epidemic, [must] do so by recognizing the affect of the epidemic on all aspects of people’s lives, not just health, and seek to identify areas where support will have a positive impact”. As Figure 1.1 indicates, HIV/AIDS has many dimensions which influence the livelihood of the household.

1.6 Organisation of the Dissertation

This dissertation consists of five chapters. Chapter one covers the introduction which provides an overview of the study. The next chapter reviews the literature on the impact of HIV/AIDS on the elderly by looking at national and international studies. Chapter three focuses on the methods used in the study. Chapter four present the key findings. The final chapter focuses on the conclusion and recommendations for future policy.

Chapter 2

Literature Review

2.1 Introduction

This chapter will present a review of the literature relevant to the study. It will draw on literature from studies across the globe, particularly in developing countries where HIV/AIDS prevalence is high. There are a number of difficulties encountered by the elderly when caring for HIV/AIDS infected individuals in their households. This chapter will cover sub-topics such as carrying the burden of providing care to sick person, stigma and discrimination, difficulty of supporting their household and extended household, HIV/AIDS among the elderly, sources of support, and coping strategies.

2.2 Carrying the burden

Most studies have shown that the elderly are carrying a huge burden. Many older people face the consequences of AIDS-related illness and deaths among their own children and other relatives as well as wider social and economic changes that have occurred as a result of the epidemic (Hosegood & Timaeus, 2006). Studies show that the increase in mortality among their children places both social and economic pressures on elderly parents. The burden of care for HIV-positive adults and children orphaned by AIDS frequently falls on elderly people (UNAIDS, 2006: 15). In a study conducted in Zimbabwe on the impact of HIV/AIDS on the elderly, it was found that this problem remains under-reported (Mall, 2002). The study revealed a number of difficulties encountered by the elderly who are caring for HIV/AIDS infected individuals, including carrying them, giving them food, bathing them, administering medication, and transporting them to clinics and hospitals (Mall, 2002). In another study, more than 70% of HIV infected individuals were found to be cared for by the elderly whose ages range from 60 and above (May, 2003). The survey was aimed at exploring both the social and economic impact of HIV/AIDS on elderly people, specifically in Sub-Saharan Africa (May, 2003). This study identified two ways that HIV/AIDS affects them. Firstly, HIV/AIDS places a burden on the elderly and secondly, they are themselves at risk of contracting the infection. Older persons are most often the default caregivers when AIDS strikes a family in developing countries (May, 2003). In countries such as Malawi and Zambia there is a loss of the social security system when a family member(s) becomes sick

and dies, thus leaving the elderly with no one to support them (May, 2003). May (2003: 17) gives an example of “a grandmother in Zambia who had been supported by her daughter, but when the daughter and her husband both died of AIDS, she lost her only source of income and inherited five grandchildren”. Both of these scholars highlight finance, stigma and socio-economic stress as the main challenges experienced by the elderly when caring for HIV positive adults and grandchildren. Senior caregivers often face difficulty feeding, clothing, housing and properly caring for their grandchildren and are also burdened by their own failing health, and often, broken hearts (Ssengonzi, 2007). Older people describe the burden of care as the need to provide medication, cleaning materials, lifting, washing, feeding, cleaning the sick, fear of infection, fetching water, and because they worry about leaving the sick behind, older people miss the opportunity to work in the fields (Nhongo, 2004).

In another study conducted in Zimbabwe on the impact of HIV/AIDS on the elderly, the majority who were caring for AIDS victims revealed that HIV/AIDS was causing financial burdens because sick people often need to be taken to the clinic or hospital and that requires money (Mupedziswa, 1997). The study made use of in-depth interviews with older parents who were caring for HIV infected adult children and their grandchildren (Mupedziswa, 1997). In Zimbabwe, almost two-fifths of older-age care-givers stated that they had experienced physical illness after the death of people living with HIV/AIDS (PHA) in their care (Mupedziswa, 1995). This has shown that HIV/AIDS has a great impact on the lives of the elderly, especially those who are facing the huge difficulties and responsibilities of caring for HIV/AIDS infected individuals in their households.

A study conducted in Togo found that HIV often presents additional burdens for older caregivers, in that it can infect several family members and multiple generations simultaneously, thus limiting the source of income upon which older Africans typically depend for support (Moore & Henry, 2005). The study found that elderly people in Togo were carrying tremendous burdens. In another study conducted in Uganda among elderly who were caring for HIV/AIDS infected individuals it was found that the elderly were the main caregivers of the HIV-infected persons and their families (Ssengonzi, 2007). This study also found that elderly women were more likely to be caregivers than elderly men. These harsh circumstances substantially add to the burden of caring for an AIDS-sick person, and to the patient's suffering and loss of dignity (Moore & Henry, 2005).

The responsibility for day-to-day patient care is borne primarily by elderly females, who reported a higher rate of physical ailments than male respondents - perhaps an indication of their disproportionate contribution to the care responsibilities (Ssengonzi, 2009). Studies carried out in Thailand and Cambodia find that elderly women are more likely to be caregivers than elderly men, especially when providing care such as bathing, feeding a sick person and giving a sick person treatment (Knodel et al, 2006). Elderly men were only available for financial assistance. In fact, in both countries elderly women were personal care providers for sick adult children. In Thailand, the mothers are the main personal care providers even when both parents were alive at the time of their child's illness while in Cambodia the predominance of mothers as main caregivers is solely the result of fewer fathers being alive to do so (Knodel et al, 2006). This indicates that HIV/AIDS places a greater burden on elderly women than elderly men. In Namibia, the percentage of orphans cared for by grandparents has increased from 44% in 1992 to 61% in 2000 (UNAIDS, 2004). Grandmothers are bearing the epidemic's burden in isolated and remote rural conditions (Chazan, 2008b).

2.3 The economic impact on the elderly

The AIDS epidemic places economic pressure on some of the elderly (Knodel et al, 2006). This argument is based on a study conducted in two countries: Thailand and Cambodia. Knodel et al. (2006: 3) finds that "while there are adverse economic effects in both countries, the situation is worse for parents in Cambodia because of that country's extensive poverty and lack of government social protection mechanisms". In addition, Knodel (2003) finds that in Thailand parents are the most likely to pay for their ill adult child's medical treatment. Apart from paying medical costs, the older parents are also expected to bear the costs for the funeral burial. Interruption of economic activities results in a cut in the total income of the household.

A study conducted in Thailand and Cambodia on elderly parents of persons with HIV found that the elderly were having difficulties when it came to purchasing treatment and covering the funeral costs when the sick individual dies (Knodel et al, 2006). The study found that many parents did not have sufficient savings or cash in hand to cover expenses and were thus forced to go into debt or sell assets or possessions (Knodel et al, 2006). The study found that due to their desperate situation the elderly were even forced to consider loans which in turn

accumulate more debt because of huge interests. This then leads to a situation where they have to sell their assets. Knodel (2003) finds that large proportions of parents who paid expenses said that it placed a severe burden on them, although, again, considerably more so in Cambodia than Thailand. “The higher level of hardship and the more common borrowing of money and selling of assets to cover expenses reported in Cambodia likely reflect the more widespread poverty and weaker formal safety net there than in Thailand” (Knodel et al, 2006: 50).

A study conducted in the Mpumalanga province of South Africa which is one of the poorest provinces in South Africa found that HIV/AIDS places a high burden on poor elderly people (Makiwane, 2004). The impact of the HIV/AIDS pandemic on the elderly has been hugely underrated and has placed a heavy burden on older people, in addition, economic hardships such as high youth unemployment (Makiwane et al, 2004). Caring for an adult child living with HIV/AIDS or losing an adult child who was an earning member of the family to HIV/AIDS may have severe economic impacts such as loss of financial support through transfers, increased expenditures, especially catastrophic health expenditures, and perhaps a forced return to the labor market (MRC & UNAIDS, 2006). For many elderly to go back to the labour market can be challenging since they may suffer degenerative diseases such as arthritis and hypertension which make it difficult to work again at their age. Another challenge is that there are very few companies which are willing to hire elderly people. This means acquiring a job can be very difficult.

The elderly spend most of their income on household necessities and education of grandchildren; 9% are caring for sick young adults living in the household; 22% are staying with grandchildren whose own parents are either dead, or away in the urban areas on a long-term basis; 20% take care of children six years or younger, and 46% take care of children between the ages of six and eighteen (Makiwane et al, 2004).

Another study was conducted in Warwick Junction, located in KwaZulu- Natal, which is a province that is most affected by HIV/AIDS (Chazan, 2008b). This study was targeted at grandmothers from various areas especially rural areas, to work in Durban as street traders. These grandmothers either have primary education or no education at all. The data was collected using in-depth interviews. Many grandmothers reported having a huge financial burden, due to the large number of people they were supporting. Due to AIDs grandmothers are supporting growing numbers of children and grandchildren and losing income-earning

family members (Chazan, 2008b). These women also reported that they were struggling to pay medical costs for sick individuals, funeral costs and food, because the money they make is simply not enough. The majority of grandmothers reported that they were suffering from degenerative illnesses such as diabetics and hypertension which makes it difficult for them to care for sick individuals and other family members. Chazan (2008b) finds that they were concerned about who would take responsibility for their care if they could no longer work, and what would happen to their families when they eventually died. One old woman reported that she was supporting 19 people. Chazan (2008b:6) states that this woman took on responsibility for not only orphans but also provided personal care for the terminally ill. One study in Uganda and another in Zimbabwe found that terminally ill AIDS patients were often cared for by their parents and that this care causes financial burdens, mostly associated with the care of an ill adult and the care of orphans (Dayton & Zimmer, 2003).

In many African societies, burials and mourning for the dead takes several days among affected families (Ntozi & Nakayiwa, 1999). The preparations for funerals take a long time because there are funeral rites that need to be performed, and this may also mean additional costs. Funerals often involve significant costs for surviving parents and affect their economic well-being in the same way as the costs involved prior to the death of the child (Knodel, Witkins & Van Landingham, 2003). Apart from the emotional trauma of losing a child, the elderly also have to worry about the costs which not only cover burial but also transport and food for the people who attend the funeral. It costs the country's citizens almost seven times more to bury a person than to care for a sick relative, and certain households affected by HIV/AIDS spend up to 30 times more on funerals than on health care (Palitza, 2006). This study found that costs include payment to a undertaker of about R 325, with additional expenses arising from cleansing and other rituals, mourning garments, radio and newspaper advertisements announcing the burial, beasts for slaughter and meals and transport for mourners (Palitzer, 2006). A study conducted in South Africa shows that households with AIDS-related deaths were spending most of their income on treatment and funeral costs (Oppong, 2006).

In South Africa and other Sub-Saharan Africa countries such as Lesotho and Botswana, many grandmother-headed households rely on meagre old-age pensions to cover food, medical care, and supplies for HIV and AIDS-infected family members, and grandmothers stretch their pensions as far as they can, but it can be very difficult to support a large household on a

small stipend (Lewis, 2007). The death of prime age adults is likely to alter the household composition and in particular, the positioning of older persons in the household (Monasch & Boerma, 2004). Supporting a large number of people including extended family members or relatives is another challenge faced by elderly people. The majority of households rely on old age pensions to buy household commodities and this places huge pressure on the elderly as they have to stretch their pensions to meet household needs. Apart from taking care of sick adult children, there is also the responsibility of taking care of grandchildren and other sick relatives who might be residing in the household. Often AIDS affected sick adult children return to their parents' houses when they become too sick. (Knodel et al, 2003). A study in Thailand found that once people get married they leave their parents' homes to start their own families, particularly in urban areas, and return to their parents' homes in the villages when their sickness reached advanced stages. Some elderly state that they not only have to look after their sick children but also other co-residents who might be a risk to themselves, need to be cared for.

Thus the rural elderly have the potential to play a pivotal role in holding together farm households, ensuring food security, and the survival of orphans (Rugalema, 1999). A study conducted in more than 16 African countries on the living arrangements for people who are aged 60 years and above, found that elderly were living with grandchildren and other extended family members who are often their dependents (Faoud, 2004). Interestingly, this study found that in most countries the elderly were living in extended families. Time spent by the elderly performing household chores increases following an adult's death, and their participation in wage employment falls; no evidence has been found of increased participation in farm work among the elderly (Faoud, 2004).

2.4 The social impact of HIV/AIDs on the elderly

Social relationships may be disrupted by the time-consuming demands of care-giving (Knodel, 2003). The sickness of individuals in a household may force the elderly to change their lifestyle. For instance, if she or he used to spend most of their time socialising, he or she may have to reduce this time and pay more attention to a sick individual. Knodel (2003:2) finds that "stigma can lead parents to withdraw from normal community life or cause others to avoid socializing with them". A study conducted in South Africa shows that the living conditions of many elderly who are caring for sick individuals were not large to

accommodate all the members of the household (Makiwane et al, 2004). The cumulative effects of AIDS, unemployment, displacement and chronic illness are reflected in the grandmothers' changing household structures (Chazan, 2008a). This is especially so if the house is not big enough to accommodate many people. These conditions may force the elderly to change their household structures. For instance, they might be forced to offer their bed to sick children and they would themselves have to sleep on the floor. Caregiving can lead to social shunning by people who have misgivings about being near the caregiver or the adult child with AIDS (Knodel et al, 2003).

2.5 Stigma and discrimination

AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS (UNAIDS, 2009). However, it is worth mentioning that even people who are close to HIV positive individuals can become victims of such discrimination. Knodel, Witkins & Van Landingham (2003: 6) state that "if community members avoid attending the funeral or act in offensive ways at the funeral (e.g., refuse food, avoid being near the corpse), parents suffer socially and emotionally". In this way the elderly may not only suffer the pain of losing their children but also the pain of being discriminated against by their neighbours and community at large. AIDS, even more than other causes of young adult death, can compound parental misery because of the intense suffering of the ill son or daughter, especially during the terminal stage, and the accompanying stigma that is sometimes attached to the illness (Knodel, 2002). Some elderly women state that apart from the pain of seeing their children suffering, they also have to face the negative reaction from neighbours and community members who often exclude them from economic activities because of the stigma attached to HIV/AIDS. Knodel et al. (2003) find that adverse reactions of others in the community toward the parents, either during the time of the child's illness or after the child's death, could result psychological, economic and social trauma. This study also found that the elderly may sometimes start small businesses to generate income, but if members of the community know that there is a HIV positive member in that family they may become reluctant to come and buy due to the fear of the contamination Knodel et al. (2003). This indicates that stigma and discrimination can have a negative impact on the household income. The study also suggests that even within the family some members may practice discrimination against the sick individual (Knodel et al, 2003).

Another study conducted in Canada found that stigma is no longer a major concern because neighbours and community members were supportive of families with HIV infected individuals (Knodel et al, 2006). In Canada neighbours and community members showed sympathy and support towards families known to have HIV positive individuals (Knodel et al, 2006). In addition, Knodel et al (2006:49) found that “the relative absence of strong and widespread stigmatization likely facilitates parents' willingness and ability to provide home-based care to their HIV-infected adult children as well as those who return at the terminal stage, having migrated from the parental home”. Stigma is one of the major challenges faced by the elderly who care for HIV infected individuals. Some of these elderly people are even accused of being involved in witchcraft. One of the most critical impacts of stigma is that it robs the family of their only “social security” system; productive members are taken out of the equation when they become ill and die, leaving children and the elderly to fend for themselves (Munthali, 2002 cited in May, 2003).

2.6 Impact of HIV/AIDS on living arrangements

Nhongo (2004:2) states that “the problem with AIDS is that it is disrupting the family structure in an irreversible way and shifting the weight and pattern of responsibilities to those of its members that are ill placed to perform them or thought that they had done their part”. A study conducted in Lome, Togo, found that HIV/AIDS places a great deal of pressure on the elderly who are caregivers to people with HIV/AIDS (Moore & Henry, 2005). They felt frustration, despair, and isolation because HIV/AIDS has changed the family structure and social expectations. HIV/AIDS has changed social norms which carry the expectation that younger generations should take care of elderly people. There is a great Togolese proverb of Mossi, which says “one brings a child in the world and cares for him/her until child has his/her teeth, in hope that a child will care for parents until they lose theirs” (Moore & Henry, 2005).

HIV/AIDS can reduce the supply of adult children with whom to live, thus reducing the tendency to co-reside with such children. It might also increase the supply of grandchildren who require support, thereby increasing the tendency of the elderly to co-reside with their grandchildren, and lastly, for those who live with their grandchildren, the epidemic could change the balance from co-residence as a fostering arrangement to co-residence as a response to the death of the grandchildren's parents (Dayton & Zimmer, 2003). Clearly these

changes can have a great impact on the lives of the elderly because the death of adult children may mean loss of income while the increase of grandchildren may put financial and social pressure on the elderly.

The epidemic has led to major threats to economic and social stability, as family structures are being uprooted in cultures where elders traditionally depend on working-age adults as caregivers (Hsaio, 2007). This is to say that normally adult children are expected to provide care to the elderly but, due to the high HIV/AIDS prevalence among this group, the situation is reversed. In most African countries, the elderly live with their children. When adult children become sick and die, this means that the elderly often become orphaned elderly. The studies carried out in more than 18 African countries shows that many elderly do not have assistance in caring for their sick adult children (Hsiao, 2007:2).

A study conducted in Lome, Togo found that AIDS is having huge impact on family structures because many families are left with the elderly as household heads (Moore & Henry, 2005:148). Family structures may be permanently altered, and thus have reduced capacity to respond to the needs of their members (Moore & Henry, 2005). The majority of the elderly in the study revealed that they were not getting any support from extended family members to care for sick individuals.

2.7 Lack of information

Many studies found that the elderly do not have proper information about HIV/AIDS. A study conducted in Botswana shows that older people are not well informed about HIV/AIDS. Some elderly in Botswana believe that HIV/AIDS is a curse from the ancestors and that they may need to slaughter a goat or cow for forgiveness (Knodel et al, 2003). The elderly were approximately as likely as their younger counterparts to have ever known a person with HIV or AIDS, and 7.5% of the older sample ever lived with or cared for a person with HIV or AIDS (Knodel et al, 2003). The lack of information often exposes elderly to the risk of HIV infection while caring for people living with HIV/AIDS. Some elderly express the fear of getting infected when caring for their adult children but do not fear infections when caring for their HIV infected grandchildren.

Recent trends show that more and more elderly people are getting infected by HIV/AIDS. This may be better explained by the fact that many who care for HIV infected individuals do

not have knowledge about how to protect themselves. Caring for HIV/AIDS individuals can expose the elderly to infectious diseases such as tuberculosis that may exist in HIV positive individuals. The fact that some of the elderly are ignored by HIV/AIDS programmes also lays them open to infection, both as carers and as sexually active people (Nokes 1990). The other reason could be that there have been very limited awareness programmes which promote understanding about how HIV infects or affects elderly people. Studies conducted in three countries in Africa, Latin America and America on the impact of HIV/AIDS on the elderly found that when adult children start to get sick they may not tell their parents the truth about the illness (Knodel et al., 2003). This then increases their risk of HIV infection because they do not use protection whilst caring. Knodel et al. (2003) state that the AIDS epidemic impacts older persons through multiple pathways that is likely to have potential consequences for their emotional, economic, physical, and social wellbeing. In this study they found that large numbers of elderly people who die due to HIV/AIDS related illness have been providing care for infected individuals and this shows how ignorance among the elderly has put them at risk of contracting the virus. A study conducted in Togo found that some of the elderly who were caring for HIV positive individuals were scared that they might get infected when providing care to HIV infected persons (Moore & Henry, 2005). Most elderly people do not even know the safe way of looking after AIDS patients yet many of them have children who are suffering from AIDS and are often left to cater for infected orphans (Wemys, 2009).

A study conducted in Uganda on the challenges faced by elderly people caring for HIV infected persons, found that there has been limited information on understanding how HIV/AIDS affects the elderly in Sub-Saharan Africa (Ssengonzi, 2007). Elderly women are most often the main caregivers of HIV-infected persons and their families. This study found that elderly women may have to provide care even to people who are in advanced stages of HIV/AIDS and this makes them vulnerable to HIV infection because they do not use protection such as gloves. The challenges of caring for sick patients are compounded by the responsibility of caring for children affected by HIV/AIDS (Ssengonzi, 2007). This study also found that it is elderly women who are more likely to take care of grandchildren if their parents die. A study conducted in Kenya on the socio-economic impact of HIV/AIDS on the elderly found that elderly women who traditionally own little property in Africa, are especially at peril, with even fewer resources than elder men (May, 2003).

In Zimbabwe, in 1997, 43% of households with AIDS orphans were headed by grandmothers, a significant emerging phenomenon which is described as a skipped generation (Foster, 1997). This is further supported by Knodel & Ssengtienchail (2002:3) who assert that “grandmothers are more likely than grandfathers to provide at least some personal care, and are also more likely to be a main personal care-giver”. This may be better explained by the fact that grandfathers are always away from home so they are more likely to provide financial assistance rather than care. For this reason, in some villages in Zimbabwe they refer to HIV/AIDS as the “grand-mother’s disease”. Caring for a sick person can demand a great deal of energy and is also emotionally demanding. Older women generally suffer most from chronic poverty and lack of resources (Fouad, 2001).

2.8 The emotional of HIV/AIDS impact on the elderly

Losing a child can be emotionally very draining to parents. It is even more terrifying for parents who have seen their child deteriorating in front of them. They take their responsibilities very seriously, and they often suffer distress when they are not able to provide enough food and clothes, or are able to meet their grandchildren’s educational needs (Mall, 2005). Emotional distress over an adult child’s suffering and decline during illness, and grief following the child’s death is universal; numerous studies indicate that the death of an adult child is among life’s most emotionally distressing events (Knodel & Ssengtienchail, 2002). The elderly may suffer from emotional strain from seeing their children die before them. This is further supported by Mall (2005:4) who found that “older parents can also suffer feelings of blame, shame and guilt about their children’s situation”. The study also found that the elderly who care for people living with HIV/AIDS suffer from emotional strain and psychological trauma. Knowing that they have lost their source of income can also exacerbate emotional stress in the elderly especially since the sickness can last a long time before the person dies.

Nhongo (2004) finds that the trauma of the death of their child is followed by feelings of desperation as to how to adequately cope with the surviving orphans at a time when resources are scarce and other forms of support are limited. Nhongo (2004) finds that in addition some of the sick were mentally distraught and fought with their caregivers. This results in more emotional trauma for the elderly because they have to witness their children losing their grip on reality. Knodel & Ssengtienchail (2002:4) observes that “the illness and death of an adult

child also means that any current or future financial support from the child is lost. In a similar study conducted in Uganda, the findings were similar to those in Thailand”. Caring for an HIV infected individual can be emotionally draining to the elderly, since the illness can be long process. For an elderly to see his or her child being depleted in front of them can be depressing. The strain of caring for people living AIDS in the final stages of the illness can be harrowing and tiring, and take a toll on the older person’s own health (Mall, 2005).

Some of the elderly may feel guilty about failing to teach their children about HIV/AIDS and how to protect themselves from getting infected. Nokes (1990:120) argue that “an atmosphere of mourning is created as parents attempt to cope with the impending death of their adult child”. Sadly, the death of an adult child can be a traumatic experience for the elderly. A prospective view of the impact of AIDS on grandmothers shows that they are shouldering today’s burdens, while the next generation of grandmothers is disappearing (Chazan, 2008a).

2.9 New roles as parents to orphan children

The majority of elderly citizens in Sub-Saharan Africa endure the pain of seeing their children suffering from HIV/AIDS. They often have to bury their own children. After the burial, elderly citizens have to assume the role of being parents again. Emotional strain may result from negative community reactions toward foster grandchildren or concerns about the costs of childcare, and physical strain and exhaustion can result from additional work required to cover these costs (Knodel et al, 2003). A study conducted in Kenya, indicates that elderly people who care for AIDS orphans are faced with enormous difficulties (Nyambedha, Wandibba & Aagaard-Hansen, 2003). Elderly caretakers face major difficulties in caring for the orphans in terms of schooling, food and medical care (Nyambedha, Wandibba & Aagaard-Hansen, 2003). Many older persons are suddenly faced with a situation where they have to resume a parental role and all the responsibilities that go with it, while having no reliable source of livelihood, and in many cases they do not have the physical capability to undertake such responsibilities (Nyambedha, Wandibba & Aagaard-Hansen, 2003). Another study that was carried out in Zimbabwe found that the majority of caregivers for AIDS orphans were grandmothers. This reveals that the elderly play a great role in taking care of grandchildren when their parents die. They support terminally ill adult children and their orphaned offspring in poverty, without recognition, and often in poor health (May, 2003).

A study carried out in Zimbabwe found that more than 60% of orphans were cared for by grandparents and these parents struggle economically because the majority of them are no longer working but rely on their pensions to survive. Apart from the loss of loved ones, AIDS is taking away those that originally provided support to older people and leaving a large number of orphans, the majority of whom are being cared for by older people (Nhongo, 2004). Despite the pivotal role they play in caring for sick adults and orphans, they felt that government was doing nothing to assist them. Nhongo (2004) states that the large impact of HIV/AIDS on older people and the roles they play in caring for the sick and orphaned children are rarely recognized. Many older people simply do not have the resources to cover the cost of bringing up several grandchildren and satisfying their own needs (Nhongo, 2004:6). A study carried out in South Africa found that many elderly people express the challenge of feeding many orphans (Makiwane et al, 2004). In another similar study in Tanzania the elderly who were caring for AIDS orphans, found that the children were not satisfied with the support they were getting from the elderly because their needs were not fulfilled. Nhongo (2004) attests that older people echoed these sentiments, saying that as they care for the sick and later strive to generate sufficient income to meet food and other basic needs, they are unable to care for their grandchildren in the way they would like. This was further supported by Drimie (2002:21), who affirms that “often orphans are left in the care of their grandparents across South Africa”. A study conducted in Uganda among the elderly who were caring for orphans, found that more than 56.7 % felt the main challenge was lack of money and parental care (Ntozi & Nakayiwa, 1999).

2.10 Sources of support

A study carried out in Kenya finds that the elderly may employ various forms of support. Older grandchildren, especially boys, might be forced to withdraw from school and look for jobs in order to support the household. Nyambedha, Wandibaa & Aagaard-Hansen (2003) state that elderly worked for wealthier members of the community, they often worked long hours for little pay. In some cases children become the subject of exploitation. Nyambedha, Wandibaa & Aagaard-Hansen (2003) state that orphans also engage in a range of activities such as charcoal burning, fishing, mining and sometimes cutting wood to sell as firewood in order to earn an income. Another study carried out in Eastern Cape, South Africa on the elderly as HIV/AIDS caregivers used focus groups as the data collection method. The respondents were men and women aged 60 and above who were caring for both sick adult

children and AIDS orphans in their households. In elderly headed households pension grants are an important source of support. Social grants, especially pensions, have been reported as the main source of income in many studies. This study also found that neighbours and relatives, particularly extended families, are a good source of support and this includes community organisations such as non-governmental organisations. A small number of elderly caregivers reported being involved in income generating activities such as raising chickens, gardening, sewing, or selling drinks to supplement the family income (Nyambedha, Wandibaa & Aagaard-Hansen, 2003). Other elderly are reported to have joined “stokvels”, which is a rotation form of payment and at times elderly people have to send some money to the “stokvel” which leaves them with no money to buy household commodities. Nyambedha, Wandibaa & Aagaard-Hansen (2003: 43) found that “respondents also report providing psychological and emotional support to each other by talking about their problems and that appears to provide the elderly with the opportunity to identify with and relate similar experiences, although there are concerns about confidentiality”. The church was also identified as a source of support, especially for offering prayers during times of hardship. All of the caregivers interviewed were church members and frequently acknowledged their belief and trust in God to improve their situation, and they also encouraged the children in their care to pray (Nyambedha, Wandibaa & Aagaard-Hansen, 2003).

Other studies claim that the elderly may rely on extended families or relatives for support. Social networks help reduce the potential financial burden on the elderly (Weinreb, 2002). This highlights the importance of the role played by extended families and relatives in providing support to the elderly. A study conducted in one of the villages in Kenya called Amambisi community shows that HIV/AIDS was having a huge impact on households headed by the elderly. This study finds that because of the high costs of treatment, some people have resorted to crime by stealing livestock in order to sell it and buy treatment for the sick individuals (Foad, 2003).

2.11 Coping strategies

Due to the inability of the elderly to earn an additional income, they seek alternatives in instances where they have to transport a sick person to the clinic or hospital. Many older people resort to selling important assets to pay for medical expenses (Knodel, 2006). This is further supported by, the Commission on HIV/AIDS and Governance in Africa (2009: 15)

which states that “income is lost and assets are sold or rented in order to get cash”. It becomes even more difficult in poor communities, where the elderly have no worthwhile assets to sell. The elderly may be forced to reduce expenditure on basic commodities and to spend their income on medical treatment expenses. One of the alternative methods usually adopted is a reduction in the purchases of clothes and food. This state of destitution may lead to an undesirable situation with children being withdrawn from school or their school entry being delayed in order to save money for treatment. The survey also indicates that in half of the cases in which a parent gave care to the ill child, one or both parents had to either stop or reduce their economic activities (Knodel et al, 2003).

2.12 Summary

This chapter has shown that elderly people are carrying a huge burden because of HIV/AIDS. In the fight against HIV/AIDS elderly people have constantly been ignored, yet are clandestinely suffering. This chapter has identified a number of difficulties encountered by the elderly when caring for HIV positive individuals in their households. A number of studies reviewed in this chapter show that the impact of HIV/AIDS on the elderly has been largely neglected. The chapter discusses the role of the elderly becoming parents again by looking after their grandchildren. Lastly it discusses some of the coping strategies the elderly often adopt to cope with the situation.

Chapter 3

Research Methodology

3.1 Introduction

This chapter will present the research methodology employed in the study. It will start by providing a brief description of the area where the study was carried out, namely Ugu North District. The study draws on qualitative data from in-depth interviews. In total, 12 interviews were conducted among men and women aged 60 years and above. The chapter will start by providing a brief demographic profile of the province where the study was conducted. It will also examine the setting of the study and then outline the sampling strategy, the process of data collection, and the analysis. Lastly it will discuss the limitations of the study.

3.2 HIV/AIDS in KwaZulu-Natal

KwaZulu-Natal is situated on the east coast of South Africa, bordering Mozambique and Swaziland in the north, Mpumalanga and Free State in the west, the Eastern Cape in the south and Lesotho in the south west (Bradshaw et al., 2000). The province of KwaZulu-Natal is one of the most populated parts of South Africa with more than 10 million people. It is estimated that two million out of 9,4 million KwaZulu-Natal residents live mostly in rural areas (Chazan, 2008b). While some of the population is relatively affluent, the province is still marred by high poverty rates, inequalities in the distribution of income between various population subgroups, and high levels of unemployment (Statistics South Africa, 2001:2). KwaZulu-Natal has a high prevalence of HIV/AIDS. Approximately 16% of the population in the province is living with HIV/AIDS. The largest numbers of HIV positive people live in KwaZulu-Natal (1.5 million) and only an estimated 43% of those in need of antiretrovirals are on treatment (Statistics South Africa, 2001:2). This figure shows that KwaZulu-Natal is carrying a huge burden of HIV/AIDS; therefore it needs a great deal of attention when it comes to intervention programmes. It is predicted that HIV/AIDS will place a substantial burden on the future economic development of KwaZulu-Natal and the Republic of South Africa, confirming the need for policies to curb the economic costs of this pandemic (Statistics South Africa, 2001:2).

3.3 Profile of Ugu North district

This study was conducted in the Ugu North district. The Ugu North district is the third largest district in the province of KwaZulu- Natal. The word Ugu is derived from the English word 'Coast'. The area is estimated to have a population of more than one million, mainly Zulu speaking people. It is known for being a tourist destination because of its welcoming environment with subtropical forests, conserved nature, cultivated land and beautiful beaches. TB and HIV are the major causes of morbidity and mortality in the area Ugu North district. The area has a shortage of health facilities and social welfare structures, and those that exist are understaffed.

The Dumisa Community Centre is the only community centre in the area. The Dumisa Community Centre also operates as a clinic; on Thursdays local people can consult with nurses and there are HIV focus group sessions on certain days. The Dumisa Community Centre has only one lay counselor who serves more than 80 people a day. The lack of health care facilities has led to many health care workers leaving the area. The shortage of health care workers has contributed to patients who are on antiretrovirals to stop taking their treatment which in turn can lead to the problem of medication resistance. This has led the community to respond by establishing a community based care and hospice centre. The district is facing a shifting morbidity profile, which reflects a population in the midst of an epidemiological transition showing a mix of infectious diseases, chronic diseases and hygiene related health issues (Statistics South Africa, 2001).

Figure 3.1



Source: Hall (2004)

3.4 Qualitative methodology

This study relies on qualitative methodology. McRoy (1995:79) states that “qualitative methods are holistic in nature and the aim is to understand the social context and the meaning that people attach to everyday activities”. The qualitative research paradigm in its broadest sense refers to research that elicits participant accounts of meaning, experience or perception (McRoy, 1995). This study used qualitative research methodology because it is very useful when wanting to explore people’s social and economic experiences. Qualitative methods usually produce data in the form of words rather than numbers. Qualitative methods are especially useful in the generation of categories for understanding human phenomena and the investigation of the interpretation and meaning that people give to events they experience (Plikinghorne, 1991). Qualitative research helps in understanding difficulties encountered by people because of the nature of the investigation.

Qualitative methods rely on open-ended questions which help respondents to avoid predetermined sets of answers; this gives respondents much more freedom to respond in their

own words. It also allows the researcher to be flexible in probing questions, especially when some issues arise during the interviews. It also requires a researcher to employ certain skills during the interview such as listening attentively to the respondent. Probing skills help in establishing what is being said. The use of qualitative methods encourages respondents to provide more detailed information than quantitative methods. Qualitative methods can be time-consuming and very costly. Building trust with respondents often requires a well trained researcher, especially if the topic is sensitive.

3.5 In-depth interviews

Boyce (2006:1) define “in-depth interviewing as a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation”. An in-depth interview becomes vital when collecting data on individual’s personal experiences. Often in-depth interviews use open-ended questions which makes it easier for a researcher to make a broad investigation of the topic. In-depth interviews are essential in helping respondents to tell their story. In-depth interviews are a method of interview where questions can be changed or adapted to meet the respondent's intelligence, understanding or belief. Interviewing is the main mode of data or information collection in qualitative research (De Vos, 2001). It merely extends and formalizes conversation. It allows the researcher and participant to explore an issue in more detail (De Vos, 2001). This technique was very important because it enabled the respondents to be relaxed since the interviews are not formal. In-depth interviews afforded the researcher the opportunity to obtain a greater understanding of the socio-economic impact of HIV/AIDS on the elderly

In-depth interviews are a very effective way of gathering data because it is quicker than using other tools such as questionnaires or focus groups and they are also useful in understanding social phenomena. Because I obtained permission before I commenced with the interviews, the respondents felt a sense of worth. In-depth interviews provide a more relaxed atmosphere in which to collect information-people may feel more comfortable having a conversation you know about their program as opposed to filling out a survey (Boyce, 2006). This in turn is more likely to produce accurate and honest responses.

However, like any data collection tool, in-depth interviews have disadvantages. For instance, interviews can be very time-consuming and some respondents can be annoyed if the agreed amount of time is extended. The respondent can also limit the amount of information provided, especially if the researcher keeps on probing. However, this may be overcome by building trust at the beginning of the interview. Another disadvantage of using in-depth interviews is that respondents might not be honest. Working with a large amount of data obtained during the interview is very time consuming especially during the transcription and data analysis phases. Interviews are time-intensive evaluation activity because of the time it takes to carry out the interviews, transcribe them, and analyze the results (Boyce, 2006). In-depth interviews do not necessarily represent the situation of the whole population.

Generalization

The aim of qualitative research is not to obtain a representative sample. The results may not be generalizable to the entire population of the elderly but they nevertheless provide some useful insights into the impact of AIDS. If the study has more cases it becomes easier to draw general conclusions without any fear of bias. Glazer & Strauss (1967:6) argue that “the main aim is that from the beginning of data collection the material is analyzed by coding and memo-ning”. Glazer & Strauss (1967:3) further argues that the preliminary results lead to considerations about what further material (including new interviews, field observation and documents) is needed to confirm or support the initial results. This suggests that it is essential to use different methods to check if they provide similar results.

The interview setting

All the interviews were conducted at the home of respondents; they felt more comfortable to discuss HIV/AIDS-related issues in their private spaces rather than in groups. Before the interview I talked to respondents about the content of the form in case they could not read. Secondly, I made sure that respondents signed the consent form which stated the aims of the study, gave assurance of confidentiality, and also informed respondents of the fact that they had a right not to respond to questions which made them uncomfortable. In the consent form I stated that respondents were free to withdraw from the study if they wish to so. De Vos (2001: 301) stated that “consent can be obtained during preliminary interviews when finalizing arrangements, or a verbal consent may be recorded at the beginning of the interview”. For this study ethical approval was obtained from the University of KwaZulu-

Natal. I also explained the way I intended to conduct the interviews by tape recording responses. I got permission from the respondents to use a tape recorder and I also assured them that information provided would remain confidential. It was vital during this stage to create rapport with the respondents. As a researcher I also had to demonstrate listening skills, by showing keen interest in what the respondents were saying. The interviews were carried out in one area in the Ugu North District. Josselson (1998:8) states that “at the root of unstructured interviewing is an interest in understanding the experience of other people and the meaning they make of the experience”. This afforded me the opportunity to have a broad understanding of the experiences of the elderly who are caring for terminally ill individuals, as well as the difficulties of taking care of AIDS orphans. Perhaps the greatest and most fundamental skill that a researcher should develop is the ability to analyse an interview while participating in it (De Vos, 2001).

Sampling procedure

Random sampling is a method of drawing a sample of a population so that all possible samples of fixed size n have the same probability of being selected (De Vos, 2001). The representativeness, it means that the sample should have approximately the same characteristics as the population relevant to the research in question. This was taken into account during the sampling process; gender and age, for instance were vital variables for this study. The targeted respondents were men and women aged 60 and above, who were caring for HIV infected individuals in their households. I worked closely with Khanya Hospice, which is an organisation that works closely with families who care for HIV positive individuals. Khanya Hospice was very instrumental in allowing me to gain access to the respondents. The nursing manager of the hospice provided me with a sampling frame that contained a list of the elderly who were caring for people infected with HIV/AIDS. I must state that it is not simple to ensure representativeness but random sampling tries to ensure that every case in the population has an equal chance of being represented. Sampling is done to increase the feasibility, cost-effectiveness, accuracy and manageability of the prospective survey (De Vos, 2001).

Generally there are two sampling procedures, namely probability and non-probability. For the study I chose probability because it is more convenient, cost-effective and feasible. Probability sampling is where the sample is selected in such a way that it is possible to

estimate the probability that each element, unit of analysis, or person being studied has a chance of being represented (Babbie, 2001). This simply means that each case has equal possibility of being selected. For this study I used systematic random sampling, this sampling method is very convenient and it is important to ensure representativeness. The researcher can decide from the beginning that each tenth case on an alphabetical list will be selected, e.g. numbers 10, 20, 30, 40, 50 and so on (De Vos, 2002). In addition, Babbie (1990:85) states that “systematic sampling is regarded as having a higher value than simple random sampling at least as far as convenience is concerned”. In the study, the nth respondents were selected, depending on their number. The sampling frame list had 24 cases. I then decided to select every second respondent until I obtained 12 respondents to participate in the study. All the interviews were tape recorded, transcribed, and translated.

Research participants

Participants of the study were men and women aged 60 and above, who care for HIV/AIDS infected individuals in their households. This includes the elderly who care for both sick adult children as well as orphaned grandchildren. The study was conducted in Ugu North district, KwaZulu-Natal. The area is mainly dominated by isiZulu speaking people; hence all the interviews were conducted in isiZulu. The mean age of the respondents was 63 years. None of the respondents were employed during the time of the interviews. However, a few were involved in activities in the informal economy (for example, selling fruit and vegetables). In addition, all respondents were receiving an old age pension. Respondents were living with more than one grandchild and others were living with extended family relatives.

3.6 Ethical considerations

De Vos (2000: 63) attests that “ethics is a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offer rules and behavioral expectations about the most correct conduct towards experimental subjects”. Anyone involved in research needs to be aware of the general agreement about what is proper and improper in scientific research (Babbie, 2001). For this study I ensured that respondents knew the purpose of the study and I was very honest about the amount of time I would require from them during the interviews. The interviews lasted about 45 minutes to 60 minutes each. Most importantly, I told them that all the information shared with me would remain confidential. Obtaining informed consent implies that all possible or adequate information about the

investigation, the procedures that would be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, is given to potential subjects (Williams et al., 1995). In addition, De Vos (2000: 65) attests that “participants must be legally and psychologically competent to give consent and they must be aware that they would be at liberty to withdraw from the investigation at any time”. To begin with, I briefed the respondents about the study and its objectives to ensure that they were familiar with the study. This enabled respondents to take a decision about whether or not participate in the study because I told them that their participation was voluntary. I also informed respondents that they had a right not to answer questions that they did not feel comfortable answering, and they had a right to withdraw from study at any time. According to Sieber (1982:67), “confidentiality is a continuation of privacy, which refers to agreements between persons that limits other’s access to private information”. For this study the researcher asked the permission of the respondents to use a tape recorder during the interviews and I assured them that all the information provided to me would remain confidential. To further ensure confidentiality and anonymity I used codes instead of using really names.

3.7 Data analysis

All the interviews were tape recorded and field notes were taken during the interviews. Interviews were conducted in isiZulu so that the respondents were able to express themselves freely. The interviews were later transcribed and translated into English.

This study used interpretive analysis as a tool to analyse the data that was gathered. The interpretive approach presumes that people’s subjective experiences are real, that we can understand each other’s experiences by interacting with them and listening to what they tell us, and that qualitative research techniques are best suited to this task (Terre Blanche, 2002). Interpretive analysis involves reading through the data repeatedly, and engaging in activities of breaking the data down, thematising and categorizing, and building it up again in novel ways (elaborating and interpreting) (Terre Blanche & Kelly, 1999). The objective of interpretive research is to piece together people's words, observations, and documents into a coherent picture expressed through the voices of the participants (Jessup & Trauth, 2000). During the analysis stage, I identified the major themes and then recorded them into different sub-headings or categories to make it easier to compare similarities and differences.

3.8 Reliability

The validity of the data gathered during the interviews was ensured by additional information I gathered in discussion with a lay counselor and caregivers working in the community centre and hospice centre, about general challenges faced by the elderly who care for HIV infected individuals. This was further supported by recent studies carried out in some developing countries such as Cambodia, Zimbabwe and Thailand on the elderly who are caregivers (Knodel, 2006). I also made use of recent information available from the internet and publications from the World Health Organization and Population Council. To ensure the reliability of the study, the interviews were only conducted by the principal investigator of the study in order to maintain a high quality of data. All the interviews were tape recorded and field notes were taken during the interviews for key points. This helped to ensure the reliability of data.

3.9 Limitations of the study

The stigma attached to HIV/AIDS led to some of the respondents being reluctant to openly participate in the study. However, after the researcher outlined the objectives, they were willing to participate. Some respondents felt that some information was personal and embarrassing to reveal, for instance the shortage of food, hence they were reluctant to reveal that they sometimes beg for food from their neighbors. Identifying respondents aged 60 and above was very difficult because they often become very reluctant to speak to strangers, especially when discussing HIV/AIDS. The in-depth interviews were also very time consuming. Due to the high sensitivity of the topic some respondents did not speak openly during the beginning of the interviews.

3.10 Summary

This chapter provided detailed information about the methods used in the study. This is a purely qualitative study using in-depth interviews. Since the study dealt with a sensitive issue, the researcher employed necessary skills during the interviews including establishing rapport, showing empathy and listening attentively. Ethical considerations were also discussed namely informed consent. Lastly, the limitations of the study were also outlined.

Chapter 4

Findings

4.1 Introduction

This chapter presents the findings from the qualitative study conducted in the Ugu North district, KwaZulu-Natal. It examines the socio-economic impact of HIV/AIDS on the elderly who are caring for HIV/AIDS infected individuals in their households during the time of the study. The chapter will start by providing a biographical profile of the respondents. Thereafter it will describe sub-themes such as living with an HIV infected person, stigma and discrimination, caring for grandchildren, and coping strategies.

Table 4.1 outlines the socio-economic and demographical profile of the respondents. The study consisted of elderly people living in the Ugu North district in KwaZulu-Natal. The respondents were all black. The respondents either had lived or were living with HIV/AIDS infected individuals in their households. The sample consists of 6 elderly females and 6 elderly males aged 60 years and above. The age of the female respondents ranged between 60 to 67 years, while the age of male respondents ranged between 61 and 64 years. The marital status of the female respondents was as follows: two respondents were married, two were never married and two were widows. As for the male respondents, all were widowers with the exception of one man who was living with his spouse and children. All the respondents were living with their grandchildren, and some of the grandchildren were HIV positive. All respondents were receiving a pension grant during the time of the survey, which was their main source of income.

4.2 Table 4.1 Characteristics of respondents

Gender	Age	Marital status	Number of children	Number of HIV positive deceased individuals	Number of grandchildren
Female 1	67	Widow	7	1	3
Female 2	60	Married	4	1	3
Female 3	69	Never married	4	1	3
Female 4	62	Married	3	0	4
Female 5	65	Widow	5	1	4
Female 6	66	Never married	2	0	1
Male1	61	Widower	6	1	4
Male 2	67	Widower	1	0	3
Male 3	63	Married	1	0	1
Male 4	66	Widower	4	0	1
male 5	62	Widower	3	0	1
Male 6	64	Widower	2	1	3

4.3 Living with an HIV positive person

This study found that all respondents were either living or had lived with an HIV positive person in their household, and some of the respondents were caring for AIDS orphans. All respondents stated that living with an HIV positive person was placing a great deal of economic, social, emotional, and psychological pressure on them. The elderly stated that living with an HIV infected person was very demanding and stressful.

“Yes, there were two people but since my daughter passed away she left her daughter with me, who is also HIV positive” (IDI#1, Female.)

“My daughter is living with the virus and she is very sick. My wife is also not well but for her it is not a virus, it is hypertension and arthritis” (IDI#3, Male).

This study found that most respondents were living with extended family members in their households. For an elderly person, caring for a sick person is viewed as a problem, and they agreed that it demanded a great deal of time and money because of the high number of required visits to a clinic. In addition, some complained that their caregiving activities were putting a strain on their own health. However for some of the elderly, caring for a sick person was not an additional burden at all. Most were caring for a sick child or family member.

“He is my sister’s son, so he is like my son too” (IDI#5, Male).

“She has since passed away and then I decided to raise her children, because they are like mine” (IDI#5, Male).

Some of the respondents stated that they had been living with an HIV infected person for a long period of time. One respondent further stated that her daughter had been sick for a long time and her health situation was not improving. Some of the respondents stated that after caring for their sick children for a long period of time, the children eventually die and leave behind their children with their grandparents.

“She was very sick for a long time, and I was moving up and down with her, trying to get her better. When I thought she was getting better, she just got sick for two days then she was hospitalized. After that we received a call from hospital saying that she is gone. That really broke my heart” (IDI#1, Female).

“My daughter is HIV positive and she has been sick for a long time” (IDI#4, Male).

“My son just discovered that he is HIV positive after a long illness of which we believed it to be TB. He did not receive the news well because after that he

just became sicker” (IDI#6, Male).

“Before he died, nurses at the clinic asked him who will take care of his children if he dies, he said my mother will look after them” (IDI#4, Female).

One respondent expressed the demands of living with a person who shows all the symptoms of HIV/AIDS but is reluctant to be tested. For an elderly person living with an HIV infected person, seeing one of your children starting to show HIV symptoms can be very worrying. One elderly woman cried when she explained how her son has been suffering but continues to refuse to go to the clinic. She said she knew that he was HIV positive because of the symptoms he displayed:

“I took him to the clinic because he was showing similar symptoms as his older brother who died from HIV/AIDS. At the clinic they convinced him to take the HIV test and thereafter he was tested HIV positive. It is very difficult to tell a young person that he is not well because you might never know how he will receive that” (IDI#3, Female.)

This study found that some of the respondents were not only living with a HIV infected person, but there were also individuals within the household who were experiencing other health problems. The respondents stated that these individuals also needed their attention and it was difficult for them to provide care to a number of sick people; they carried a double burden.

“My wife is also sick, therefore I am also caring for two sick people and it is too much for me but I have to see to it how they are doing all the time, especially my daughter who is HIV positive” (IDI#3, Male).

“I am caring for two people in this house, one is HIV positive and the other one is a mental retard. They all need my attention; they need to be given food and given treatment on time. Their clothes need to be washed. On top of that I have my own sickness which requires my attention as well. It becomes even more difficult if I am not feeling well because I am unable to help them” (IDI#4, Female).

4.4 The social impact of HIV/AIDS

The study found that HIV/AIDS has brought about many changes in the lives of the elderly. They stated that ever since they began caring for sick persons in their households they have seen drastic changes in their lives. The health status of the sick persons in their household had forced them to abandon all of their previous activities such as selling fruits and vegetables during pension days, in order to focus on the sick person. If a sick person had been a breadwinner, the elderly are more likely to assume new responsibilities that were previously taken care of by the HIV infected person in the household. This was also affecting their social activities because they did not have time to spend with their friends any longer.

“It started like a minor flu, she then became more and more weak and at that time I was already caring for her because she was no longer able to do most things by herself. After hearing that she is HIV positive I became more worried because I knew that AIDS kills” (IDI#5, Male).

“Ever since she became sick many things have changed. Now I have to do household duties by myself because my wife is also not well. In most cases my granddaughter assists in cooking and cleaning the house” (IDI#6, Male).

“After she passed away I had to do all her responsibilities, like taking care of her children. All three of them are not receiving grant because they do not have birth certificates, hence I cannot access child support grant” (IDI#1, Female).

Many elderly no longer have free time to spend away from home with friends, or visit relatives who stay far away because the sick person needs them all the time. Along with this, they feel it is their responsibility to look after the sick person because they were either their own children or grandchildren. This study found that when HIV/AIDS strikes a household it was the elderly who were likely to be most affected because they are always at home.

“Now I have to always be here at home for the sake of my granddaughter. I had to make sure that she gets food and she takes her treatment on time and

sometimes I forget and she will be the one who reminds me to give her treatment” (IDI#1, Male).

“ Now I need to be here at home all the time for my son's sake because his health situation has become worse and I do not even get time to see people, as I used to do before” (IDI#5, Female).

4.5 Difficulties encountered by the elderly

This study found that respondents faced a number of difficulties when caring for a HIV infected person in the household. There are a number of challenges mentioned by the elderly people including shortage of food, stigma, discrimination, and lack of resources.

“Shortage of food is the main challenge, because it runs out very quickly and she needs to eat food before she takes her treatment. Another problem is she needs to visit clinics and hospitals very often which means I need to have money” (IDI#3, Female).

“The main difficulty I have encountered is mostly when he becomes very sick at night and there is no money to hire a car to the clinic. That requires me to wake people at night to assist me to push the wheel- barrow; because I no longer have the power to push the wheel-barrow. They then need money to buy some beer and then I will have to give them from the little money left” (IDI#5, Female).

The elderly respondents argued that the sick person may present different difficulties at the same time, which then turn out to be overwhelming for the caregiver. These difficulties often leave the caregiver helpless. Some of the respondents said they do not have the necessary skills to take care of sick individuals. The lack of information about caring for sick persons often leave the elderly vulnerable to the risk of HIV/AIDS. This is a major challenge faced by many elderly people. The overwhelming demand of taking care of a sick person requires a great deal of attention.

“She sometimes asked to be taken outside but if it is too hot, that makes her more sick “(IDI#1, Female).

Naturally the difficulties encountered by the elderly respondents differ according to their economic levels. For instance some respondents do not have problems in terms of buying food and sending sick individuals to the clinic when necessary. Other elderly people neglect their own needs in order to take responsibility for the wellbeing of their family and grandchildren. All the household needs are met through pensions.

“It is very rare where you would find that there is nothing, whenever I got money I make sure that I buy enough food to last us until I get more money. HIV positive need food before he takes his treatment and grandchildren need food because they cannot go to school with an empty stomach” (IDI#6, Female).

“I buy them food and their school uniforms; they never sleep on an empty stomach (IDI#1, Female).

One respondent mentioned the challenges she encountered when providing care to her daughter. She said she has tried everything she could do to show that she loves her daughter despite being in the situation she is in. She stated that her daughter sometimes becomes angry and wants to fight with everybody.

“One of the most stressing thing is that she would request certain food and I would try by all means to get it only to find out that she is not eating even when I tried to feed her, she just refused. There was a time when she went two days without eating. Sometimes she would even accuse us of not looking after her” (IDI#1, Female).

Some respondents, especially those who do not have anyone to assist them, said it would be better if there was another individual assisting them. They felt that having someone to help them would lessen the number of duties they had to undertake, as they felt overwhelmed by the amount of work.

“Sometimes I even wish there was someone to assist me, because it is really difficult for me” (IDI#3, male).

“Caring for two sick people, it is really hard my child, even though sometimes my granddaughter does help but she is young and most of the time is out at school, at least if there was somebody who could be always around it would be better” (IDI# 6, Male).

4.6 Stigma and discrimination

The majority of the respondents in the study reported that they were the victims of discrimination because they were known to be caring for HIV positive individuals in their households. This study found that respondents often endure embarrassing comments from neighbours and community members because of this. Some respondents were fearful of informing their neighbours about the HIV status of sick individuals.

“Whenever I go to the clinic to collect treatment for my son, neighbours start to make humiliating comments “oh here is this woman again who always go to the clinic and we don’t know what is her problem”. I guess they want to me explain myself to them how am I suffering, because I am doing everything I could in order for him to get better” (IDI#1, Female).

“This really frustrates me, because I do not know whether I should tell everybody about my daughter’s sickness and how are they going to help me if I told them, except gossiping about me. I cannot stop going to the clinic to collect treatment for my daughter because it is something which I know is going to help her” (IDI#6, Female).

Due to the fear of being discriminated against, an elderly person may not disclose the status of the HIV infected person to the neighbours or even to the extended families. Some respondents are not only the victims of stigma and discrimination but they also have to bear the pain of seeing their grandchildren being discriminated against or harassed by other children in the neighbourhood. The harassment and insults directed at the grandchildren affect the elderly emotionally because they feel it is their responsibility to protect their grandchildren. One respondent told the principal researcher how his grandson is

discriminated against by other children at school. It was clearly emotionally stressful for him. The discrimination directed at the sick person is also felt by other family members, especially those who are caring for the sick person.

“Oh yes, other children used to harass him not because they knew he is HIV positive, simply because they know that he is sick and weak and could not defend himself. What hurt me most was that some of the neighbours used to gossip about him, saying he is HIV positive and that is why he is having a big head” (IDI#4, Male)

“Last year my grandchild had to stop going to school because other children used to tease him and that made him hate going to school. I then decided to go to school and asked the teachers to give him back to me” (IDI#3, Male).

“Yes, I have been discriminated because even when my child was sick my neighbours did not even bother to ask how is your daughter. This was painful even during the burial of my daughter, neighbours did not even send condolences. They knew that she was sick and they did not even ask me what was wrong with my daughter and if they asked I would have told them the truth that she is HIV positive” (IDI#2, Female).

Some of the respondents believe that the lack of knowledge about HIV/AIDS in the area was the main reason why many people continue to discriminate against people who are known to be HIV positive or living with an HIV positive person in their household. Some of the respondents stated that if someone coughs people start to label that person while others avoid the person and his or her family. Stigma and discrimination are the main obstacles in the fight against HIV/AIDS. Often stigma and discrimination are associated with lack of knowledge. One elderly person stated that lack of knowledge about HIV/AIDS is a major problem in the area.

“I think people are not well informed about HIV/AIDS. For instance if they know a particular household has someone who is HIV positive, they then think everybody in that family is HIV positive. I spoke to them and I told them that what they are doing is painful to the sick person and to other household

members, but I also think that many people in this area are not educated about HIV/AIDS, if someone becomes sick and loses weight people then start to label that person as HIV infected and they then stay away from that person, even close friends avoid that person”(IDI#2, Female).

This study found that the respondents who did not disclose the HIV status of sick individuals in their households were less likely to be the victims of discrimination. For instance, some respondents believe that not disclosing the status of the sick person was a way of avoiding humiliation and embarrassment from neighbours and the community at large. Due to the fear of being discriminated against, households with sick persons opt to not let other people know about the HIV status of the sick person. The hiding of the HIV status of the sick person is used to protect the sick person as well as his or her household. In response to whether they were ever been discriminated against respondents stated:

“No, maybe it is because they do not know about my daughter’s HIV status” (IDI#5, Male).

“I have never been discriminated at all; I decided that her sickness is a family matter because I knew from the beginning if I tell one person the whole community will know about it within a day, And people will start to gossip about my family” (IDI#1, Male).

Some respondents stated that they had been isolated by their neighbours and the members of their communities. Some elderly revealed that they felt as if they are contaminated, because people avoid having contact with their household. This study found that this makes the elderly reluctant to participate in some of the community activities because no one will associate with them.

“People have a tendency of discriminating against my family because even if there is an event with some of the neighbors we do not get invited, I think they are trying to keep my family away as much as they can and that really hurts me but there is nothing I can do to change what they are doing” (IDI#3, Male).

“Whenever I go to clinic to collect treatment for my son people start to make comments, I cannot stop going to the clinic to collect treatment for my son because it is something which I know is going to help him” (IDI#6, Female).

This study found that respondents who had decided not to disclose the sick person’s status were more likely to escape harmful utterances from neighbours or from the community at large. However, some respondents argue that even though they did not reveal the status of sick persons to their neighbors, they were still receiving hostile attitudes from neighbours. The hostility is also felt by other household members, which then makes the household feel ashamed of the status of the sick person.

“We agreed that no one must know his HIV status, because I know people in this area will gossip about my son” (IDI#4, Male)

Respondents expressed the pain of seeing their sick children suffering discrimination even by some members of the family and close relatives. One respondent revealed that some of her relatives have stopped visiting her household because they do not want to come near the sick person for fear of contracting the virus.

“Ever since she became sick some of my close relatives do not come visit us here anymore, even when we told them that she is very sick they do not even bother to come and see how he is doing. That really breaks my heart” (IDI#3, Female).

4.7 Lack of support from extended family

Family support is vital if someone becomes sick within a family. Respondents in the study were living in large households with extended family members. However, very few respondents in the study reported that they were receiving support from their extended family members. One elderly woman reported that her sister is her source of support and strength.

“My younger sister understands my situation and she has been very supportive to me, she phoned every day to check how is my daughter doing and sometimes she brought food for us” (IDI#2, Female).

One respondent expressed anger towards his son-law for not supporting his grandson. This respondent argued that despite his son-law living close by, he had not even bothered to come

and check if his son had food or was even alive. This has put strain on the two families. He described his son in-law as irresponsible.

“My son-law is still alive and does not care about his child not even to call and check if he is still alive” (IDI#5, Male).

Some respondents revealed that one of reasons they were not getting support, especially from extended families, was simply because they knew nothing about the HIV status of the sick person. The respondents said they decided not to inform the extended family because they were afraid of how they were going to respond to the news and they also feared being judged.

“I decided not to tell many people about his HIV status, except his sister and his brother. We agreed not to tell many people about his sickness. As for my relatives they are not helping me with anything, particularly with the sickness of my son. They did not even go to visit him when he was at the hospital and he stayed there for two weeks in critical condition” (IDI#4, Female).

“My son never approved of the idea of telling his uncles and aunties about his HIV status because he feared that many people will know that is living with the virus and I have tried so many times to convince him to allow me to tell some of my relatives and he remains reluctant. Instead he does not want even to take his medication and that really stresses me because I have done everything I can but he is not improving” (IDI#5, Female).

A few respondents stated that they were not receiving support from extended family because their close families were living far away, so they were relying on neighbours for support. One respondent said even if he reported the situation of the sick person to the extended family, they would not bother to visit. The elderly man went on to reveal that when his first wife passed away the extended family did not attend the funeral. When asked what could be the reasons for the extended families not offering any support or attending funerals the respondents stated:

“ Maybe it is because they are far, even if I report something to them they do not even bother to come and hear what is the problem” (IDI#5, Male).

“My relatives they stays very far, hence we are not that much in contact” (IDI#1, Female).

One respondent was caring for his sister’s daughter and her daughter. His sister’s husband had passed away and he had to take care of his sister and her daughter because the sister could not afford to take care of the child alone. He further stated that he did not have close relatives in the area.

4.8 The emotional impact of HIV/AIDS on the elderly

The study found that respondents who have lost their children due to HIV/AIDS find it very difficult to accept their deaths even though their children had been sick for a long time. This was because the parents had hoped they would get better. Respondents further stated that HIV/AIDS had robbed them of their beloved children. This study found that the loss of a child can result in health complications for the elderly. Some elderly expressed the emotional pain they went through after seeing their children dying in front of them. The impact is usually not felt immediately after the child had passed away, but during the times of preparing for the burial because money was needed for the funeral.

“HIV/AIDS has robbed me of three children. I have lost three children. I still have one grandchild who is also on treatment” (IDI#1, Male)

“Even today I still call her name, because I have not accepted that she is gone, I wish God can bring her back to me again”(IDI#6, Male).

“After her burial I became very sick and my blood sugar level was very high. Ever since she passed I have not been well. I cannot even do simple things anymore like cleaning the yard” (IDI#3, Male).

One respondent explained how she went through a traumatic experience of seeing her daughter-in-law losing her mind due to the side effects of antiretroviral treatment. She revealed how she felt when she visited her daughter in-law in the hospital and found her wrapped in chains. This happened after her son had passed away from HIV/AIDS. She said until today she could not forget what she saw that day. She further stated how close she was to her daughter-in-law. She said a few years ago she had become very sick and the only

person who was there for her was her daughter in-law. She was very caring to her and her son.

“It was very painful to me, because when he passed away his wife was 7 or 8 months pregnant. Soon after that my daughter- in-law became very sick and it was after my son passed away. My daughter-in-law just lost her mind, I will never forget the day when I visited her at hospital and found her wrapped in chains and I cried. She passed away leaving behind her little child for me to take care” (IDI#3, Female).

The two elderly women revealed that ever since they had lost their children they have had health problems caused by the pain and trauma of losing a child and the painful experience of seeing them suffer from HIV/AIDS.

“Doctors told me that my blood pressure level is very high after she passed away. Ever since I have not been well, I think I would need to see the doctor because I sometimes lose energy, like in past few days I have not been well” (IDI#5, Female).

“After her death I became very sick, even now as you can see I am not well (sitting on the bed) and when children come back from school they expect me to give them food” (IDI#1, Female).

4.9 The economic impact of HIV/AIDS on the elderly

This study found that HIV/AIDS is placing a huge economic burden on the elderly. Quite a number of expenses are borne by those who care for HIV infected persons; it includes buying recommended food for the sick person, food for the family, medicine for the sick person, transport for the sick person to the clinic in emergencies, and funeral costs. The respondents revealed that they were not coping with the economic challenges brought on as a result of caring for HIV positive persons, especially since most households were previously dependent on the sick person for the household income. Respondents stated that their economic situation changed immediately after someone became sick in the household, especially if that person had been the main breadwinner.

“When she started to get sick, life changed completely and at that time I was not even at an age to qualify for a pension as I was only 58 years” (IDI#3, Female).

“Soon after he got very sick the situation got worse in this house. His sickness stopped the income here at home we thereafter relied mainly on neighbours to assist us with money to buy some food. For me that was something new because I never thought it will happen to me, to be with no food” (IDI#5, Male).

“When she became really sick, she had to stop working and come back home, that is how we stopped having an income in this house, and that time it was difficult for me to go back to Durban to look for work because I am old, there is no company that can hire me” (IDI#6, Male).

This study found that the majority of respondents had relied on the HIV positive person for their household income and other basic commodities. Some of the respondents stated that HIV/AIDS was not only taking their children away from them, but their source of income as well. The study found that a sick person was more likely to be the only breadwinner in the household. The economic impact is felt immediately when a breadwinner passes away and it becomes the responsibility of the elderly person to ensure the survival.

“My daughter was the only one who was working in this house because her father stopped working a very long time ago. My daughter used to work in one of the factories in Durban and she was very supportive, unfortunately when she suddenly became very sick there was no way that she could continue with her work because she was very weak and she was missing a number of days at work so the employer would not give her the money without work” (IDI#6, Male).

“Ever since my son passed away it has been very difficult, he was the only one who managed to bring something on the table, and I had problems with my

pension. Soon after he got very ill the situation got worse because there was no income here at home. We rely mainly on neighbours to assist us with some money for food and return it back whenever I get the money” (IDI#4, Male).

“She was very helpful to the whole family because she used to buy us food whenever she got paid. Even for her siblings she used to assist them with clothes but ever since she started to get sick things have changed” (IDI#4, Male).

Some respondents stated that when the sick person is no longer able to bring income into the household, they are then forced to assume the responsibilities of the sick person. These responsibilities include supporting grandchildren and other dependents. For instance, when a sick person has children the elderly have to provide for the needs of these children. There were s also sometimes other people in the households who were dependent on the elderly and these people needed to be given food and other commodities. In most cases the elderly live in large households with a number of family members. The elderly often assume responsibility for these extended family members, especially if the household relies on a pension grant and there is no one working.

“I have three people who are my dependents; my wife, my daughter and my granddaughter. All these people are my responsibilities. It was better when my daughter was still working because she used to support all of us, but I had to see to it by myself and it is not easy” (IDI#3, Male).

“I am now looking after her daughter. The huge challenge is that she had three children from different fathers and none of them was willing to support the children. After her death I had to take over all her responsibilities by taking care of her children and the last born is very sick. All three of them are not receiving grant because they do not have birth certificates, hence I cannot access the grant” (IDI#1, Female).

“Her sickness really affects everyone here at home because we were depending on her for food and important things for the house, like these chairs and sofas were

brought by her” (IDI#1, Male).

“My son is not the only one who is sick, my brother-law is also sick as well. Even though it is not HIV/AIDS, he needs attention as well” (IDI#5, Female).

The majority of the respondents stated that they now rely on state cash transfers. However, they quickly stated that the money they received from the state was not enough since a sick person may need to visit the doctor very often. Pension and disability grants are insufficient to cover the household needs of the large number of people in their households. All the respondents were receiving a pension grant from the government and this is their main source of household income. This money had to cover all the needs of the sick individuals, as well as the needs of the elderly.

“I rely on the pension grant I received from the government. However, the amount of money I am receiving is not enough to meet the needs of all my family. With the little money received from the government I have to buy food for the house, send children to school, and pay for their school fees and uniform” (IDI#4, Female).

“I used the little money that I received from the government to hire the car to take him to the clinic” (IDI#5, Female).

“There is nothing except the pension and child support grant for my grandchild; if it was not for that little money I receive from the government I do not know how we would be surviving” (IDI#4, Male).

This study found that if the respondents cannot get money from neighbours, they are then likely to fall into the trap of borrowing money from loan sharks; this usually involves paying large amounts of interest. Some of the respondents stated that they had accumulated large debts and did not know how they were going to pay them back. Failing to pay the debt leads to a further desperate situation of borrowing more money in order to pay debts.

“My neighbours are also poor as my family so they do not have money to lend me. My cousin directed me to someone he knows who can lend me the money, which I have to return with interest. I was not able to pay the last month’s outstanding amount, I guess I had try to pay it quickly otherwise he will never help me again” (IDI#4, Female)

“I normally borrow the money from my neighbours but they do not always have money as they sometimes struggle as well, I then went to loan sharks and it needs to be paid back with huge interest” (IDI#1, Male).

Some of the respondents stated that to get the recommended food for the sick was very difficult because they did not have money to buy such food which tends to be very expensive. They said that they were even struggling to buy ordinary food for the household because food prices had gone up. Some of the respondents revealed that they were tempted to borrow money and buy the recommended food because they hoped that it might help the sick person. *“At the clinic, they say I should give her the food with vitamins, but where I am going to get the money to buy the food with vitamins” (IDI#6, male).* Some of the respondents stated that the recommended food requires extra money which they do not have.

“The other challenge is that I cannot afford the food that they suggested I should give him, because I do not have enough money to buy such food, it is very expensive for me. He has to eat whatever food is cooked here at home as much as I would like for him to have those vitamins but there is nothing I can do” (IDI#5, Male.)

“Nurses at the clinic said I should avoid giving her food with cooking oil and curry powder because it is not good for her health. They then recommend that I should give her fruit, vegetables and 100 per cent fruit juice, because I want to see her getting better I tried to get her the recommended food but it is only for a short while because the money ran out very quickly. I was then forced to borrow the money from people, and sometimes I felt like I am bothering other people” (IDI#4, Male).

Many respondents expressed that life is very difficult for them, especially since they can no longer engage in economic activities because of their health problems. There were three things the study observed: the deterioration of the personal health of the elderly caregiver, the inability to care for the sick person because of the deterioration of the caregiver's health, and the inability to participate in alternative economic activities because of caregiving activities. Many of the elderly suffer from degenerative diseases such as hypertension, arthritic and swollen knees. This study further established that the demanding work of caring for sick people does not allow the elderly to be involved in any activities because the sick demanded their attention most of the time. The majority of the elderly is old and frail and can no longer get involved in activities that are physically demanding.

“I am very old now I cannot even go to the field and plough because I am arthritic. I normally ask people to plough for me and then give them money from the very little pension I am receiving from government” (IDI#1, Female).

“At my age I cannot even go and look for a job, even if my neighbours can give me some job to do ironing or cleaning It would be difficult for me because I have my own sickness and need to take care of my grandchildren”(IDI#4, Female).

The elderly respondents stated that when a sick person becomes seriously ill they need to be taken to the clinic or hospital very quickly which requires hiring a car since an ambulance can take a long time to arrive. One respondent observed that on occasions when her daughter had been sick, the ambulance arrived four or five hours later, and sometimes not at all. She said this happened when she had no money to hire a car. One respondent revealed that she sometimes spends money on traditional herbs because friends recommended it. The respondent said much as she believes in traditional herbs, she also found them to be very expensive because she relies on a pension grant.

“I even went to the traditional healers who asked me to buy certain herbs for R150. People said his herbs can help my daughter. I bought it twice and I soon realized that it was costing me a lot of money, I then had to stop” (IDI#1, Female).

4.10 Caring for grandchildren

The majority of the respondents were caring for sick persons who were most often their children and sometimes also their grandchildren. They all agreed that caring for grandchildren was very challenging at their age. Despite having mentioned that they find it demanding to look after the grandchildren they however did not regard it as an additional burden. The majority stated that they began to take care of them from a tender age. This study found that the high prevalence of HIV/AIDS among the young generation led to a situation whereby elderly had to assume the responsibilities of being parents again at their age. When their adult children passed away their grandchildren in most cases become the responsibilities of the elderly person in the household. This study further established that grandchildren were also living with HIV/AIDS. HIV/AIDS affects children in two ways; losing their parent(s), and possibly being HIV infected as well. In some cases, the elderly respondents were caring for both sick adult children and grandchildren who were HIV infected as well.

“Raising a child at my age has been very challenging, my granddaughter is always sick and she needs a great deal of attention. Because she is also HIV positive I have to make sure that she takes her treatment on time” (IDI#2, female)

“The death of my daughter left a burden on me because when she died she was having a small child” (IDI#1, female)

“My grandchild is HIV positive; she was born HIV positive because her mother died when she was three months old. Ever since she has been sick, she has sores all over her body. I have been going in and out of clinics and hospitals to see the doctors and that requires a lot of money” (IDI#3, female)

This study found that caring for the grandchildren was quite demanding for an elderly person, since they often become sick and need to be taken to the clinic, where there are long queues. The elderly respondents revealed that HIV infected grandchildren were more demanding, particularly when it comes to taking their treatment and especially for grandchildren attending school. They also stated that at times grandchildren refused to take their treatment. To ensure that grandchildren took their treatment on time was the elderly caregiver's

responsibility. Another challenge faced by the elderly is that they were also suffering from memory lapses. As a result they themselves are forgetful and it is very difficult for them to remind their grandchildren to take their medication at prescribed times.

“Some days I also forgot to tell him to take his treatment as the nurses instructed me to do and sometimes he went to play and return late and he misses his treatment” (IDI#2, female).

“My other concern is that he does not want to take his treatment. When I tell him not to forget to take his treatment he just asks me why he is the only one taking treatment not other children” (IDI#5, male).

Some of the respondents who were caring for grandchildren with AIDS revealed that they had not informed their grandchildren about their HIV status. They find it hard to tell their grandchildren the truth; one elderly man thought that his grandson was still too young to know that he is HIV positive. Another elderly man said he felt guilty about the fact that he has yet to tell his grandson that he is living with the virus. He further stated that he had tried many times to tell his grandson the truth, but is too scared. This has been bothering him for quite some time now. He stated that despite his efforts to get social workers to assist him in resolving the problem, his efforts were in vain because they could not help him. He related an incident while they were watching a television programme that showed images of HIV positive people and the grandson said if he found out that he was HIV positive, he would kill himself.

“I never told him the truth as to why he is taking treatment. I do not know where to start; it is really difficult for me. My other concern is that he does not want to take his treatment and when I tell him not to forget to take his treatment he just says why he is the only one taking treatment. Why I am the only one taking pills all the time not other children” (IDI#5, Male).

Grandchildren need a lot of attention, including their need to be taken to school. There are a lot of school needs which include school uniforms and school fees. All these expenses rest on the elderly and unfortunately become too much for an elderly caregiver who relies on a pension grant from the government.

“I have to buy food for the house, send children to school, pay their school fees and uniform” (IDI#4, Female).

“They go to school and come back to report to me that at school they need, this and that. Teachers said these are not school shoes and all these things needs to be address by me” (IDI#6, Female).

“Children also need school uniform, and I also need to pay back loans with a huge interest” (IDI#5, Female).

Some elderly people expressed further difficulties about caring for grandchildren, especially children who have lost their parents. To lose a parent can be a traumatic event in a child's life; hence a child may need a great deal of attention. The lack of resources was another challenge faced by the elderly when caring for grandchildren, especially if they are HIV positive. The study found that even though grandchildren were more likely to receive either a child support or disability grant, the money was never enough to cover all of the grandchildren's and other household needs. Another difficulty encountered by the elderly was the lack of health facilities. The unavailability of ambulances is a major difficulty for the elderly that were caring for a sick person or grandchildren.

“I do not want to lie to you; it is very difficult to care for an HIV positive person. Usually HIV positive people need to be taken to clinic now and again that requires a lot of money. Sometimes I do not have money to take my granddaughter to hospital and sometime I have to borrow money from other people in order to be able to take her to the hospital” (IDI#3, Male).

One elderly woman said because she has problems with her legs, she does not attend school meetings for her grandsons. This woman said she sometimes had to ask someone to go and stand in for her. This indicates that the elderly caregivers find it hard to keep up with the needs of their grandchildren. Respondents argued their grandchildren need someone like to check their school work from time to time. In most cases the elderly may not be able to monitor the progress of their grandchildren because of their own lack of education. At school

it can be very difficult if they do not understand the situation of the children, for instance sick children may perform poorly at school. This can be stressing to an elderly caregiver who wishes to see his or her grandchildren progressing at school like other children. Due to the fact that their grandchildren become seriously sick this very often means they have to miss classes because they need to be taken to the clinic.

“Sometimes I also need to attend school meetings; because my knees are painful. Hence, I am unable to attend school meetings, even though I wish to do so” (IDI#6, Female).

“Last year my grandchildren had to stop going to school because other children were teasing him, and the teachers did not bother to discipline other children for mistreating my grandchildren” (IDI#3, Female).

One elderly man said he did not believe his grandson would still be alive today because of his health condition when he was a toddler. He further states that his grandson was still young when his parents passed away. He said at the beginning he was not sure what made his grandson so sick, until nurses at the hospital advised him to take his grandson for an HIV test. He said at the beginning he could not understand how a child of that age could be HIV positive. Nurses then explained everything to him after he took his grandson for an HIV test and he was tested HIV positive. It was very difficult for him to accept the results.

"Taking you back when he was still young, I must say it was very difficult for me because he needed nappies and I did not have the money, he needed infant milk and I did not have money to buy it, a lot was needed (IDI#4, Male)

However, this study found that grandchildren were also playing a vital role within the household in assisting the elderly to care for either a sick parent or younger siblings. This shows that grandchildren are not only a burden to the elderly but also play a pivotal role in the household. Granddaughters prove to be key role players in helping the elderly with day-to-day activities. One elderly man states that his granddaughter has been supportive in terms of helping sick people in the household.

“In most cases me and my granddaughter will be helping each other with things like cooking and cleaning the house” (IDI#3, male).

4.11 Coping strategies

This study found that elderly caregivers were using various coping strategies in order to come to terms with HIV/AIDS. Since the household's income is mainly derived from pension and child support grants which are spent on treatment rather than food, households are likely to be without food long before they receive their pension. One elderly woman said she relied on her sister for support because she could not cope with the demands on her household. This shows that extended family members are playing a vital role in helping affected families to cope with the demands of caring for a sick person. The elderly who are struggling financially opt to borrow the money from friends, neighbours, or loan sharks in order to cope with the demands of caring for the sick person and other basic household commodities. Some of the elderly felt that they were bothering their neighbours by continually borrowing money from them.

“Whenever the situation goes beyond my power I borrow the money from neighbours and pay them back when I get my pension grant” (IDI#2, Male).

“If I do not have money I borrow from my neighbours and in some cases you find that even my neighbours do not have money themselves” (IDI#5, Female).

This study further revealed that when some of the elderly caregivers see that the situation of the sick person is not improving, they are likely to abandon western medicine like antiretroviral treatments, and opt for traditional herbs. One respondent revealed that he had tried traditional herbs because his daughter was not getting better, even though she took her medication regularly. The elderly man said his friends advised him to try herbs. This is an indication of the lack of knowledge about HIV/AIDS in societies.

“My friends advise me to use traditional herbs because they think it can help my daughter. The traditional herbs are very expensive at times because sometimes bottles of muti will costs me R200 and I would have to buy it because I wanted to see my

grandchild living a normal life as other children” (IDI#3, Male)

“My daughter and I used to take him to hospitals, clinics and traditional healers but came back with no help” (IDI#4, Male)

This study found that elderly caregivers lack resources, for instance clinics and hospitals were far removed from their homes and there is a shortage of ambulances to transport sick persons in times of emergency. The elderly caregivers stated that they depended on ambulances when a sick person needed to be taken to a hospital quickly. One elderly woman revealed that she used a wheel barrow when her daughter needed to be taken to a clinic and she did not have money to hire a car.

“I took her to the clinic and we will stand in the queue almost the whole day without receiving any help. Sometimes the nurses just give her a pocket with 10 pills which I think they are useless”. (IDI#4, Female).

4.12 Summary

This chapter present the key findings of the study carried out in the Ugu North district, KwaZulu-Natal, among elderly people caring for HIV infected individuals in their households. The findings of the study show that elderly are carrying a huge burden because of HIV/AIDS. Elderly revealed the traumatic experience seeing their children dying in front of them. Providing treatment to sick person, losing a child, lost of income, stigma and discrimination and caring for the grandchildren were some of the difficulties faced by elderly people.

CHAPTER FIVE

Discussion

5.1 Introduction

This study has explored the multiple impacts of HIV/AIDS on the elderly who are caring for HIV infected individuals in their households. The study draws on in-depth interviews conducted with men and women aged 60 and above in the Ugu North district in KwaZulu-Natal.

5.2 Discussion

The findings suggest that HIV/AIDS is placing a huge social and economic burden on elderly people. The majority of the respondents revealed that HIV/AIDS is a major challenge for young people, but they also admitted that they are carrying a huge burden because they have to assume responsibility for the care of sick people. They also mentioned that at their age they were hoping to rest and enjoy the fruits of raising their children. The same results were also found in a study aimed to explore how households cope with the HIV/AIDS epidemic; this study found that the elderly are ill prepared for care-giving demands, and overburdened by the enormous financial needs of people with HIV/AIDS, having been unexpectedly thrust into new roles (Moore and Henry, 2005). The same results were obtained in another study conducted in Zimbabwe, which observed that at a time in their lives when they might normally have expected to be recipients of care and support, many elderly people have no option but to become 'Africa's Newest Mothers (Nhongo, 2004).

The high prevalence of HIV/AIDS among young people places a huge socio-economic burden on elderly people. While a parent may experience grief immediately after the death of an adult child, the detrimental effects of the loss of financial support may not be felt until the elderly parent experiences an economic shock (Anglewicz et al, 2007). The present study found that the majority of HIV infected individuals in households were also the breadwinners, thus most households are left with no source of income when the breadwinner gets sick or dies. This is further supported by a study conducted in South Africa which found that two thirds of households reported loss of income as a consequence of HIV/AIDS (Henry, 2002:2). This suggests that the elderly are not only enduring the pain of losing a child but

their main source of income as well and have to rely solely on a government pension. A study conducted in the Mpumalanga province in South Africa found that more than 70 per cent of elderly people were the breadwinners of households (Makiwane, 2004).

All the respondents were pensioners and they found it difficult to secure jobs at their age and as a result were not involved in economic activities. The majority of the respondents admitted that the pension they receive from the government is not enough to cover all their household expenses. They said they use the money to buy food and medicine for the sick persons. In addition, they have to pay for transport for the sick person, and sometimes also assume the financial responsibility for the upbringing of grandchildren including payment of school fees, school uniforms, and other household commodities. Similar results were found in another study conducted in South Africa. The study found that the elderly spent most of their income on household necessities and the education of their grandchildren (Makiwane, 2004). The respondents further stated that caring for an HIV infected person was economically stressful because they often become sick and need to be taken to a clinic or hospital. This study has found that HIV/AIDS has a devastating impact on elderly people's lives and yet remains under-reported. The high HIV/AIDS prevalence among the younger generation has an indirect but huge negative impact on other household members' especially the elderly who are mostly the providers.

This study found that the elderly experience many difficulties when it comes to providing care to people living with AIDS. Bathing, feeding and washing clothes for a sick person were some of the types of care that are provided by the elderly. Unlike men, elderly women are carrying more burdens because they are involved in all these responsibilities including waking up in the early hours of the morning to make porridge for the sick person, bathing, washing and feeding them. However, this study found that elderly men who care for a sick person do not bathe and wash the clothes of the sick person; these tasks were taken care of by other family members, especially granddaughters. This is not to undervalue the role of elderly men. For instance one elderly man was caring for both his HIV positive daughter and wife who was not HIV positive but was suffering from other health ailments. The elderly, mainly women, and also a good proportion of men, are providing economic, social and psychological care and support for orphaned grandchildren a finding consistent with other studies (Hhongo, 2004).

Caring for the sick is hampered by the fact that the elderly are old and frail, which makes it difficult for them to perform some of their tasks. For instance the majority of the respondents reported that they were suffering from degenerative diseases such as hypertension and diabetics which requires medical attention. Similar results were found in another study conducted in Uganda. The majority of the respondents have a great deal of anxiety about their future health and well-being, which they attributed in most part to the HIV/AIDS epidemic (Ssengozi, 2007). This study further established that the demanding work was negatively affecting the elderly on various levels (economic, emotional, physical and nutritional), all of which impact on their health and well-being (Ssengozi, 2007). This is further supported by the longitudinal study that was conducted in rural Malawi. High morbidity and mortality in rural Sub-Saharan Africa is expected to have direct impact on individuals and their extended families, such as diverting family resources from the elderly to the working-age population and increasing the burden on the elderly to care for the sick and orphans, with implications for their long term well-being (Anglewicz et al, 2007).

The lack of infrastructural resources is another challenge established by the present study. The study found that caring for an HIV person contributes to a number of difficulties for the elderly. The caregiver often has to look after the sick person with very little available resources. Health facilities are often situated far from their place of residence so when the sick person needs to be taken to a clinic it becomes difficult for an elderly caregiver because they often have to hire a car. Due to the shortage of space in the clinic to accommodate many people, sick person are likely to return home to be cared for by household members, particularly the elderly. Some of the elderly complained about the shortage of health care workers in clinics saying that in most cases they have to queue for long hours without getting any help. One elderly woman questioned the quality of the service provided by some of the health workers saying they sometimes looked as if they were not interested in providing assistance to sick people who show symptoms of being HIV positive. One study reported that 9% of professionals refuse to care for an HIV/AIDS patient, and 9% indicated that they had refused an HIV/AIDS patient admission to hospital (Nhongo, 2004).

The lack of knowledge about how to take care for a sick person is another challenge which exposes the elderly to the risk of HIV infection. Some respondents argued that the sick person often hides their HIV status from them, and they only discover later that the person has HIV/AIDS. One elderly woman stated that her daughter only informed her about her

HIV/AIDS status few days before she passed away; the mother had been taking care of the daughter for a long time. This shows that elderly people are also at risk of getting infected while caring for the HIV positive even though the risk is minimal. They also do not use protection such as gloves when caring for the sick person.

Almost all the respondents revealed that the sick people were not living with them when they fell sick. They were either living next to their place of work or with their partners. For instance one elderly woman stated that her daughter was in Johannesburg when she received a call from one of her daughter's friends informing her that her daughter was seriously ill. After her daughter came home and from there onwards the elderly mother took care of her until she died. Similar results were also obtained in a study in Uganda which found that spouses and children generally give least assistance in patient care to adult females, probably because when women, married or single, fall sick, they go back to their parents' homes to be cared for (Ntozi & Nakayama, 1999). One elderly man reported a similar case: his son was working in Durban and living in one of the hostels but soon after he got sick he had to stop work and come home. Similar findings were noted in a study conducted in Uganda, which found that many adults who are sick with AIDS-related illnesses return to their parents' homes when they are no longer able to manage themselves (Nhongo, 2004).

The present study found that HIV/AIDS has a huge impact on the lives of the elderly. However, the elderly do not view caring for sick persons or grandchildren an additional burden although they admitted that it was challenging especially at their age. This is further supported by a study conducted in Togo, which found that although they did not complain about caring for a person with HIV/AIDS, almost all wished for an institutional solution to relieve them of the burden of providing care (Moore & Henry, 2005). In fact, some of the elderly indicated that they would be very happy if they could get some assistance in taking care for the sick. The same study conducted in Togo, found that caregivers did not report high levels of feeling trapped or held captive by their roles, and yet almost universally admitted wishing that their roles could be taken up by someone else (Moore & Henry, 2005). The present study also found that some elderly wished they could have someone to assist them with caring for the sick person. The older grandchildren are playing an essential role by assisting the elderly when caring for the sick person, especially in cooking, collecting firewood and fetching water. They also help in reminding the sick person to take his or her medication regularly.

Some of the respondents were not only caring for the sick person but their grandchildren at the same time. Almost all the respondents were living with their grandchildren, some of which were HIV positive. A number of studies have found that in Sub-Saharan Africa the majority of orphans, whether orphaned as a result of HIV/AIDS or for other reasons, are cared for by other persons, particularly older women (Nhongo, 2004). In Sub-Saharan Africa, about 13% million children have lost one or both parents to HIV/AIDS (Mall, 2005). After the death of a parent(s) children become the responsibility of the elderly person. Children need to be sent to school, and they require money for school fees, school uniforms, and transport. Even if the elderly manage to find funds for school fees, they are often unable to provide essential items such as uniforms, books and transport costs to and from school (Mall, 2005;4). It becomes even more difficult for the elderly person if the grandchildren are HIV positive. The present study found that HIV infected grandchildren very often become sick and need to be taken to a clinic or hospital. Some of the elderly stated that grandchildren struggle to come to terms with the death of their parents. A study conducted in South Africa, found that almost a quarter (22%) of all children under 15 years in households included in the survey, had lost a parent (Marahaj & Munthre, 2010). Caring for grandchildren often proves to be difficult for the elderly person because after the death of a parent, children need emotional support; the death also impacts on their progress at school. This starts soon after an adult child gets sick and can no longer provide for herself and her children.

The present study found that the elderly were also taking for care of grandchildren. The roles in the household change when the elderly have to take responsibility for caring for their adult children. A study in KwaZulu- Natal found that more than 40% of households reported that the primary caregiver had taken time off from formal or informal employment or schooling to take care of the AIDS-sick person, adding to the loss of household income and the under-schooling of girls (Maharaj & Muntthe, 2010). Many elderly admitted that caring for grandchildren is demanding and requires a lot of time. Children also suffer psychologically when their parents get sick and when they die. The majority of the grandchildren whose parents died of HIV/AIDS were also HIV positive. AIDS orphans need a great deal of care because they very often become sick.

The present study found that stigma and discrimination is a major challenge faced by elderly people when caring for HIV infected individuals in their households. They often find

themselves excluded from community activities because people avoid contact with them. Parents experience stress when neighbours or other people in the community gossip out of curiosity or fear of being infected (Knodel, 2006). The majority of the elderly reported having been discriminated against a number of times because people knew that they were living or caring for an HIV positive person. Other studies have also found that older people care for the sick, the dying, and children orphaned or made vulnerable by the HIV/AIDS pandemic (Hhongo, 2004). Some of the elderly were carrying a double burden of seeing their children being discriminated against and also suffering humiliation and embarrassment. Negative reactions to their ill son or daughter adds to the strain on parental caregivers who are typically living in the house, at least by the terminal stages of the disease (Knodel, 2006). Some of the elderly argued that they had decided not to reveal the status of the sick person due to fear of being discriminated against. Interestingly, even though they did not disclose the status of the HIV infected person, they were also still receiving humiliating comments from either neighbors or members of the community. Even though the elderly did not have any problems with collecting treatment on behalf of the sick at clinics, they agreed that places known for treatment collection were also stigmatised. They further stated that having been seen near the area for treatment was trouble on its own because it is likely to get the whole community talking. However, they said it would not stop them because they wanted the sick person to get better.

In many African traditional societies family relatives or extended families are known to provide support to all family relatives who need assistance. However, the majority of the respondents reported not getting any support from extended family members with caring for their sick children and grandchildren. The extended family had an obligation to assist orphans in the olden days: various relatives, mostly from the paternal side, would take care of them (Ntozi, & Nakayama, 1999). Recently due to the ever-increasing number of AIDS orphans, extended families can no longer cope with the demands and this leaves elderly parents with no support when an adult child dies.

The present study found that elderly people adopted different coping strategies in order to deal with the ever-growing demands of caring for an HIV infected person. As I have mentioned earlier, sick persons were often the main contributors of the household income. Losing such income puts households in a desperate position. Borrowing money from neighbours, community members and loan sharks are the main way of surviving when a

family runs out money, especially during needy times such as lack of food or the need for transport for a sick person.

This study was conducted in a traditional African society where elderly people are still attached to cultural practices and values. In such societies when someone gets sick traditional herbs are the first remedy to help the sick person get better. Even in cases where a person had been rushed to a clinic, people may still feel compelled to use traditional herbs. People also often turn to traditional healers when modern medicine fails them. The study also found that some elderly people believe that traditional herbs can help to cure HIV/AIDS. For instance, when people do not see the immediate impact of antiretrovirals, they opt for traditional herbs. This is further supported by a study that was conducted in Uganda, which revealed that most traditional healers claimed to know a cure for AIDS and many people believed them (Ntozi & Nakayama, 1999). Lack of treatment and lack of knowledge about the side effects brought about by antiretrovirals, can cause people to lack trust in the treatment and seek other alternatives.

5.3 Recommendations and conclusion

This study established that HIV/AIDS is placing a huge social and economic pressure on the elderly. The study further established that the high HIV/AIDS prevalence among the young generation has had a huge negative impact on the lives of the elderly. The study, therefore, recommends that elderly people should also be included in HIV/AIDS interventions and programmes. This includes giving them the necessary information about HIV/AIDS. Elderly people also need to be supported, especially those who are living with HIV infected persons in their households.

This study found that many elderly people are living with AIDS orphans and have to take care of them with little resources. Despite all the challenges faced by the elderly with HIV/AIDS, they are still out of the public discourse when discussions about HIV/AIDS takes place because many people believe that they are not affected. This shows that there is a great need for interventions to assist households with AIDS orphans. Governments departments and organisations that are devoted to fight HIV/AIDS and AIDS policy makers need to formulate interventions that will help to assist the affected population.

Many elderly who are caring for HIV infected persons have identified care giving of the sick as strenuous. This indicates that some of the elderly are not coping with the workload. The study therefore suggests the need for more home-based care workers who are assigned to work with households which have HIV infected persons, to relieve some of the workload of the elderly.

Another challenge that was raised by some of the elderly people was the fact that sick persons need to take medication and they cannot take their medication without food in their stomachs. Being without the food was a very common situation in some households. Some of the elderly argued that they could not provide the sick person with the recommended food because the money they receive from government is not enough to meet the needs of the sick person as well those of the household. The study therefore suggests that government should consider giving food parcels to HIV infected persons, particularly those who are on antiretrovirals from the clinics. The food parcels should be given to the people when they come to collect treatment at the clinic.

This study found that government pensions are playing a vital role in families especially those that are headed by the elderly. For instance this study revealed the most often the sick person was the breadwinner, robbing the elderly of an important source of income. It emerged from the study that some elderly women reported becoming grandmothers before they were eligible to receive pension. One elderly woman said when her daughter started to get sick, she was not yet qualified for pension because she was 58 years.

Even though all the respondents are receiving government grants such as the old age pension and the child support grant on behalf of grandchildren, these grants are the main sources of income. Some respondents had waited a long time in order to qualify for pension grants because they had not worked before, especially the women. This study then recommends that some consideration needs to be given to reducing the age criteria for pension eligibility. This study also found that stigma and discrimination is another difficulty faced by many elderly people who are known to be living with people with HIV/AIDS in their households. This study calls for more AIDS awareness campaigns to educate communities, especially in rural areas so that people will have accurate information with regard to HIV/AIDS.

Lastly, the results of this study call for more structures to support the elderly in the war against HIV/AIDS. These structures can be very important in disseminating information about HIV/AIDS. The elderly need information about how to take care of HIV infected individuals, grandchildren who are HIV positive, and those who are at risk of getting infected. It is also vital to inform elderly people how to provide treatment to sick persons, including information on the negative consequences if treatment is not taken correctly.

The study has revealed some of the socio-economic challenges faced by many elderly people who are caring or living with HIV/AIDS infected individuals in their households in the area of UGu North district KwaZulu-Natal. It was also established that elderly people who are living with HIV infected individuals in their households are carrying a double burden because they also care for grandchildren who are sometimes HIV positive. The results of this study can be vital to the HIV/AIDS policy makers, with regard to how the prevalence of HIV/AIDS in this region affects elderly people. This study shows that there is a great need to accept that HIV/AIDS is placing a huge demand on elderly people, therefore there is an urgent call for the inclusion of the elderly in the HIV/AIDS discourse.

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Interview guide

Age

Gender: Female

Male

Marital Status: Single

Married

Divorce

Ethnic Group: Black

White

Coloreds

Indian

Employment status: Employed

Unemployed

Self employed

1. Do you have any dependents?
2. If yes, how many?
3. Do you know anyone who is living with HIV/AIDS?
4. Is there anyone living with HIV/AIDS in the household?
5. What is your relationship with that person?
6. Has this impacted your household?
7. if yes, how
8. Is there anyone who has passed away due HIV/AIDS in your household and how this has impacted you socially and economically?
9. What type of care do you give to HIV infected individuals?
10. What are the difficulties have you encountered in regard to caring for HIV/AIDS individuals in the households?
11. Have you ever been discriminated in the community because you are caring for HIV/AIDS individuals?

12. What is your main source of income?
13. How do you cope, in situations of food shortages?
14. Are you getting any support from extended family members, neighbors or relatives?
15. Is there any community organizations works with HIV/AIDS infected and affected individuals such as Faith Base Organization or Non Governmental Organization with the community?
16. Are you receiving any government support, such as social grant?